

HIT Policy Committee
Meaningful Use Public Testimony
Draft Transcript
June 4, 2010

Presentation

Judy Sparrow – Office of the National Coordinator – Executive Director

Great. Thank you. Good morning, everybody, and welcome to the HIT Policy Committee's meaningful use workgroup. This will be a hearing on Using HIT to Eliminate Disparities: A Focus on Solutions. Just a reminder, this is a federal advisory committee, which means it's being conducted in public. There's audience in the room, as well as individuals listening on the telephone and on the Web. Workgroup members, please remember to identify yourselves when speaking for attribution, and the summary of the meeting will be put on the ONC Web site in within about two weeks. With that, let's just go around the table, and if the workgroup members could please identify themselves.

Christine Bechtel - National Partnership for Women & Families – VP

...systems.

Art Davidson - Public Health Informatics at Denver Public Health – Director

Art Davidson, Denver Public Health, Denver Health.

Neil Calman - Institute for Family Health - President & Cofounder

Neil Calman with the Institute for Family Health.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

George Hripcsak, Columbia University.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Paul Tang, Palo Alto Medical Foundation.

Josh Seidman – ONC

Josh Seidman, ONC.

Deven McGraw – Center for Democracy & Technology – Director

Deven McGraw from the Center for Democracy & Technology.

Judy Sparrow – Office of the National Coordinator – Executive Director

And I believe David Lansky and David Bates will be joining us for part of the meeting. Anybody on the telephone, any member on the telephone? With that, I'll turn it over to George Hripcsak.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Thank you, Judy. Welcome, everyone, and thank you all for coming today to our hearing on Using HIT to Eliminate Disparities: A Focus on Solutions. Our meaningful use workgroup member sponsor for today will be Neil Calman, and I'm going to let Neil set the charge for the day in a moment. I'll just talk a little bit about the format.

First of all, today is organized with three panels, two in the morning, one in the afternoon, the first panel being Health Literacy & Data Collection, which will be moderated by our Neil Calman; the second panel on Culture, will be moderated by Josh Seidman, sitting to my right here, from ONC; and the third panel after lunch on Access, I will moderate.

The format is that we're going to have, first of all, realize that our panelists have already submitted written testimony, which is available to the public. And our workgroup has already read that, and hopefully digested it by now. And so we ask our panelists to give five minutes of verbal comments, which kind of focus our attention and point out what's most important.

We're going to go through each panel and do everyone's presentation. Then we'll pause and have a discussion with questions for all the panelists at the end. Also realize that there's a blog that's already open, I believe, that people are welcome or encouraged to comment on and to read, so we encourage that. And I guess I'll hand it over to Neil. Thank you, Neil.

Neil Calman - Institute for Family Health - President & Cofounder

Thank you. So part of the work of the meaningful use workgroup of the policy committee has been to hold a series of hearings on a variety of subjects, and the goal is to get testimony from experts from around the country, which hopefully will conclude in a set of recommendations that the workgroup makes to the full policy committee and then to the Office of the National Coordinator. So be it known that your remarks are taken very seriously and that long after today, we'll be discussing the things that you bring up as potential recommendations as we proceed to sort of set the guidelines for the recommendations that we make around meaningful use criteria for 2013 and 2015.

HIT, like all the interventions in the way we deliver healthcare, has great potential to make things better and also have some concerns along with it about how it might make things worse, and especially we're concerned about this in relationship to health disparities. We know that people with the most difficult lives, those struggling with economic insecurity, a lack of adequate health insurance, poor education, and those living in areas that lack an adequate supply of health professionals all can gain much through the technologies that are being developed and implemented now.

The ability of health information technology to assist people in organizing their own healthcare while, at the same time, providing ... to providers to assist them in this effort is one important benefit that we have to work to attain. HIT is one technology where we have an opportunity to guarantee that people who usually benefit from technology the last are now able to benefit from it the first, and who can potentially get the greatest benefit from it.

On the other hand, there are unintended consequences that loom large, as we roll out electronic health records across the country. And, as we increasingly depend upon electronic health records, patient portals, personal health records, and other similar technologies as the main tools for which we're going to be looking at improving quality of care, increasing patient engagement in their care, connecting to public health, and care coordination because those who cannot access these tools or whose providers don't have access to them at their disposal can be left behind, possibly even further than they are now.

So therein lies our job. The HIT Policy Committee must come up with concrete recommendations now that will lead us to insure that those who need the power that HIT brings to healthcare the most have access to its tools. At the same time, we must make sure that our most vulnerable populations, whether that vulnerability is a factor of age, disability, race, ethnicity, language, literacy level, housing status, migrant status, or any other factor, that these folks are not left further behind than they've been already by our current healthcare system. We have a responsibility to make sure that the work we are doing as

official appointees of the HIT Policy Committee that in relationship to health information technology, truly nobody is left behind.

So I want to take this opportunity to thank the workgroup members, Paul Tang, George Hripcsak, Art Davidson, as well as Josh Seidman and Judy Sparrow, who have been working really hard on putting these panels together. I'm very excited about hearing from everybody. Those of us who have read through the testimonies know that there's always this richness of experience out in the community that we sort of hear little things about but don't really understand the depth in which many of the people who are going to testify have been working on these things, and so I think we're honored to have you here and other panelists during the day. And, at the end of the day, our goal will be to sit and begin the discussion about coming up with concrete recommendations that we will be hopefully making to the full policy committee.

With that, what I'd like to do is go to introduce the first panelists, and I understand that Sara Czaja is not able to be here. Is she on the phone yet?

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Yes.

Neil Calman - Institute for Family Health - President & Cofounder

She had a personal crisis, transportation, as well as a personal crisis this morning, and so we're hoping that she'll join us on the phone at some point. And when she does, maybe you could just let us know, and then we can plug her in because I know she won't be able to stay on.

The other panelists this morning, Cynthia Solomon is founder and president of FollowMe, Inc., a personal health record company launched in 2000. Her company specializes in developing customized personal health records for populations that are considered vulnerable. Products include www.mivia.org, a PHR initially developed for migrant and seasonal farm workers launched in 2003, and www.healthshack.info, a PHR developed for homeless and system-based youth launched in January of 2010. I think you're going to find her work remarkable in the scope that it's already achieved with these populations.

The next speaker will be Geniene Wilson, who is a fellow with my own organization, Institute for Family Health. She came to us with extensive experience working with refugee health clinics in Maine. She's currently a funded researcher sponsored by the New York State Department of Health with our organization. As you will hear, she's done tremendous work in developing our methods for recollecting through our electronic health record, race and ethnicity, language, and other data on our 75,000 registered patients, and is engaged in developing research to determine if this recollected data improves our analytical abilities to target our outreach to specific high risk groups of patients.

The last speak on the panel will be Silas Buchanan, who works with The Cave Institute. The Cave Institute is a global, nonprofit organization committed to assisting foundations, associations, hospitals, managed care companies, health systems, faith-based and community organizations, as well as government in resolving health disparities based on race and ethnicity, which ultimately affects all families, all communities, and all nations. He's developing a very important community-based approach to bringing HIT to vulnerable populations through organizations with whom they already have existing relationships. His work is reaching folks who may not even have any contact with their healthcare system, but who need to be engaged in understanding the benefits that health information technology can bring to them and their families and their neighbors.

I will introduce Sara if she gets here on the telephone, and why don't we start with Cynthia Solomon?

Cynthia Solomon – FollowMe, Inc. – Founder & President

Good morning. It's a pleasure and an honor to be here and share with you our work and ten years of experience and lessons learned in engaging vulnerable populations in HIT. This morning, I'm going to briefly focus on MiVia and Health Shack, so launched in 2003, MiVia now serves approximately 24,000 people in six states. It's evolved from an application that was geared specifically to migrant and seasonal workers, to a more expansive application that provides individuals and their families a way to manage their fragmented health information. It also provides an information sharing solution for hospitals and mobile health solutions that care for patients at multiple locations and across health systems.

One of the low-tech assets of MiVia and Health Shack is that members carry a photo ID emergency information card that lists conditions, allergies, and emergency contact information. The card provides a sense of security for these consumers, especially patients with special needs when they are confronted with language barriers in an emergency setting. And I can't state how important this card has been throughout the ten years that we've been using this application for both populations. Even though it's low-tech, and it's tied to the database, we have migrant workers who arrive in Sonoma, and the first place they want to go is the resource center to get their MiVia card.

MiVia works because we engage the community to help design the PHR to meet their needs. We used focus groups and consumer advisory committees, and we continually try to upgrade the PHR to address issues such as condition specific health information, coverage issues, worker safety, immunizations. Basically, the PHRs are, first and foremost, health advocacy tools. Our partners use community outreach workers and promoters to explain the PHR to the community, and this way we've been able to establish trust between the consumer and their PHR, and to learn what features and functions are important.

In 2008, we partnered with UC Davis Department of Adolescent Medicine and WIND Youth Services, a youth shelter based in Sacramento, California, to determine if MiVia would be a benefit to homeless youth and those aging out of foster care. For over 18 months, we've worked with these kids, and we listened to them and to understand what they needed. They're very similar, their lifestyles, to migrants and farm workers. And we wanted to know how they use technology in their everyday lives.

The outcome of this effort was a customized technology solution that was designed by the youth themselves, and that's called www.healthshack.info. I'm going to share with you five lessons that we learned over these ten years. It's important to understand what the consumer needs. Make no assumptions. Eight years ago, we were told that migrant and seasonal workers would never be interested in a PHR, would never be able to use it, and we've proven them wrong, the farm workers proved them wrong.

People do not like to be labeled. An example, when we first launched MiVia, we called it a PHR for migrant workers, and the migrant workers came to us and said don't call us migrants. The same with the kids, the kids don't want to be called homeless or vulnerable. They don't see themselves that way. We need to build trust through peer-to-peer outreach before any type of HIT deployment, and it's critical to partner with agencies that speak the same language and share and understand the same culture as the end user.

Consumers need to have a sense of ownership and control with assurance of privacy and consent over their health information. One way we approach that with the Health Shack project is we now have what we call granular consent. So in the PHR, we actually have the youth can give access or permission to share their medical information, but maybe not their confidential information, so we've broken it out

through health information, confidential services, and mental health. So the patient can give and take away consent based on who has a need to know.

I have some recommendations. Consumers should have access to language appropriate health information and materials in electronic format, including audio and video media. In the Health Shack, if you visit that site, these kids don't read much, but they love the videos, and we engage them by having them create the videos and create the audios, and they've very involved in that.

Individual patient health data should be made available to patients in a variety of electronic formats, including freestanding, patient owned, un-tethered, personal health records. EMR products should be required, I repeat, required to export standardized data into a patient's PHR on request. So getting to 2013 to 2015, how do we get there? We support collaboration and inclusion of community-based organizations and advocacy organizations that have direct responsibility for underserved populations. We invest in pilot project funding to explore best practices. I don't mean a 10-month grant or a 12-month grant, but 24+ months to really get that research data.

We promote consumer engagement in HIT by local and state governments by introducing consumers to HIT through culturally appropriate efforts. We provide limited, three to five years, job training funding for community-based programs such as promoters and health ambassadors and health advocates in doing peer-to-peer outreach. And I want to talk about this briefly, quickly because I think it's very important. With the youth, what we did also with MiVia, we have a health ambassador, a youth health ambassador curriculum, and we use that to engage the youth and teach them over a period of two years.

You would not today, you would not recognize the youth ambassadors, these homeless kids that we met two years ago. They are now talking across the country. They are on a roll. They are sophisticated. They are engaged. And they have potentials to go out there and get jobs, and I think that that's a very low investment for a very high return. I'll get into the research later because it's published, but I just want to finish up with a couple of things.

In terms of HIT and consumers, we need to continually rethink and retool. The solution does not mean slapping a different label on an existing product. EMR systems have been evolved from a 20-year-old legacy practice management systems, which were built to increase productivity and enhance revenue of physicians and hospitals in a fee for service environment. Today, these products have so many bells and whistles that doctors and their staff need to take classes just to learn how to use them, which in itself is creating barriers to adoption. There are simpler and more cost effective solutions, and the innovators should be encouraged and rewarded for developing them.

We need to acknowledge that the EMR industry is a billion dollar industry, and until a return on investment on engaging consumers can be developed, the push for meaningful use and for consumers will need to come from the policymakers and the payers. We have an unprecedented opportunity, as technology, patient empowerment, and health reform converge. We also have a great responsibility to protect those most vulnerable. Thank you.

Neil Calman - Institute for Family Health - President & Cofounder

Dr. Wilson? Should we jump to Sara? Sara just joined us on the phone, so let me just introduce her. Sara Czaja is a professor in the Department of Psychiatry and Behavioral Sciences & Industrial Engineering at the University of Miami. She's codirector of the Center on Aging at the University of Miami, and the director of the Center on Research and Education for Aging and Technology Enhancement, which they call CREATE. CREATE is a collaboration with the Georgia Institute of Technology and Florida State University, focused on making technology more accessible, useful, and

usable for older adult populations, and it's funded by the National Institute on Aging. Dr. Czaja has extensive experience in aging research and a long commitment to developing strategies to improve the quality of life for older adults. Sara, can you hear us?

Sara Czaja – University of Miami – Professor

Yes, I can hear you.

Neil Calman - Institute for Family Health - President & Cofounder

Thank you for joining us.

Sara Czaja – University of Miami – Professor

I'm sorry. My flight was cancelled last night, so I couldn't get to D.C.

Neil Calman - Institute for Family Health - President & Cofounder

Not a problem. Will you be able to stay on during the discussion period?

Sara Czaja – University of Miami – Professor

Yes. I get on another flight around 10:30 because I have a death in my family, and I'm on my way to Buffalo, so I'll be on until 10:30.

Neil Calman - Institute for Family Health - President & Cofounder

Great. Thanks a lot.

Sara Czaja – University of Miami – Professor

How would you like me to start?

Neil Calman - Institute for Family Health - President & Cofounder

You can just do your five-minute verbal presentation, and then we have two other presenters, and then we'll have some questions.

Sara Czaja – University of Miami – Professor

Thanks. Thank you, Neil. The focus of our research is on older adults. I think one thing that we're concerned about in CREATE is that the implementation of health information technology really has potential to increase health disparities among at risk groups such as older adults, minorities, and those of lower SCFs staff status. And I think that the potential risk for these groups include lack of access to care, reductions in health quality, as well as safety risks that might arise from inappropriate or inability to use HIT equipment or applications.

And what we're doing at our research, especially at the University of Miami, group of CREATE, has really been looking at Internet-based health applications, and we've been examining the extent to which older adults, especially at risk older adults, those who are of ethnic minority status or lower economic status are able to access, integrate, and understand health information and health applications on the Internet. I think, more importantly, the impact of access to this type of information and these applications on health outcomes and patient/physician relationships. We're also trying to understand barriers to meaningful access and potential intervention strategies such as modifications and interface designer training to remove these barriers to access.

A focus of our work right now is also on patient portals, VMR systems, and we're looking at user characteristics in addition to age such as health literacy and cognitive skills, which impact on the use of these systems, and we've also recently embarked on a project, which is evaluating the acceptability,

feasibility, and usability of a tele-monitoring system that permits wireless transfer of physiological data to health providers in clinical settings, and we're putting these systems in the homes of hypertensive, older adults, who may have been rural locations in south Florida.

I'm also working on a project actually with Neil, Chris Zachadulis, and Maxine Rock-Huff, and Neil's group at the Institute for Family Health, and we're excited about this because they're actually implementing patient portals of EMR systems, and we're looking at the literacy and usability requirements of these systems. And our goals are really to understand factors that ... adoption of these systems, and to suggest guidelines for changes in system design so that it can be used effectively by the institute's patient population. And a nice aspect of this project is we're actually working. We're working with the patients, as well as with the designers of the actual portal, and they are making changes in the design according to the data that we get from our patient interaction.

I think if I were to think about some recommendations, if we're talking about strategies that I think are important to think about when we think about access to health information IT, I think we have to, one, think about the concept of meaningful access, and meaningful access implies more than just access to equipment and technologies. It also implies understanding what these pieces of equipment, technologies, health IT applications can be used for, how to use them, having an ability to understand what kind of information is provided to be able to integrate that information and use it effectively in the management of one's own health. So we have to really think beyond just giving people access to health IT. We have to really think beyond that.

And we have to have a clear understanding of the diversity of user groups who are going to interact with health IT. This includes patients, families, healthcare providers. We need to understand their characteristics such as cognitive abilities, health literacy, technology literacy, and also the environmental context and where these systems are going to be used.

We have to think about also the demands that are being imposed on users by these systems, and I think, in concert with what our prior speaker said, it's really important to include very diverse user groups in the design and evaluation of health IT systems. We have to rely on techniques such as focus groups, usability testing, health ... load analysis to really gather requisite information that's needed for design and evaluation. And I think we really have to look at this, do this kind of research, and adopt these strategies using multidisciplinary teams. And this has to include designs of these systems, clinicians, social behavioral scientists, human factor engineers, and of course the patient and user populations. I think, also, there has to be funding vehicles to support these kinds of projects. And I think these funding mechanisms really have to be joint endeavors also where there is collaboration between the government, between academia, as well as private industries.

Neil Calman - Institute for Family Health - President & Cofounder

Thank you, Sara. We'll go to Dr. Wilson.

Geniene Wilson – Institute for Family Health – Fellow

Good morning. It is an honor to be here today, and I want to thank you for inviting me to share my thoughts and experiences. I'm a family physician working full time for the Institute For Family Health, and my work includes a combination of clinical practice, the development of a research curriculum for failing practice residents, and my own research project on health disparities.

My research, in collaboration with Dr. Calman and other researchers at the institute, focuses on the use of health information technology to better understand and address health disparities. In the course of this research, I have come to recognize the tremendous potential that health information technology brings to

our efforts to assure that all patients receive high quality healthcare. For example, reports and publications from the Institute of Medicine, the National Academy of Sciences, the Joint Commission, the NCQA, and the National Quality Forum to name a few, demonstrate that accurate and standardized collection of race, ethnicity, and language data are key to addressing health disparities.

This level of comprehensive, demographic, data collection is now feasible thanks to health information technology. Such data improves our capability to identify where and why gaps exist and to improve overall quality of care. While the collection of basic race, language, and ethnicity data is already required to meet meaningful use criteria, health information technology offers the possibility of capturing and analyzing these demographics in much greater detail. This is precisely the kind of data from which focused health disparity interventions are derived, and I recommend that the meaningful use criteria require this more constructive and details data.

This is a historic opportunity to set national standards and to finally make progress in the disparities that we have been fighting for more than 20 years. Currently, when generic quality improvement efforts are introduced, all patients benefit. But the disparity itself is unchanged. A great example of this is what my colleagues and I have seen recently at the Institute for Family Health with our diabetic patients.

Hemoglobin A1c is a measure of a blood sugar used for diabetics, and the value of less than 7% indicates good blood sugar control. We looked at our data and found that there was a disparity between whites and minorities for this specific quality measure. In an attempt to address this, we hired diabetes educators and devised other interventions to improve diabetes care. As a result, hemoglobin A1c's improved for all of our patients, but the disparity remained unchanged.

Why were we unable to reduce this gap? Are our minority patients receiving different treatment? Are there language or cultural barriers that exacerbate this disparity? To answer these questions, and to address these gaps, a more detailed and comprehensive set of data would be very instructive. Health information technology empowers us to analyze quality metrics and to break this information down by race and ethnicity in ways that were not possible in the past. This new analysis would allow us to clearly identify important distinctions within our minority patient populations and to target specific disparities with culturally and linguistically appropriate interventions.

In 2009, the Institute of Medicine published a historic report on standardizing the collection of race, ethnicity, and language data, which recommends that in addition to the traditional categories of race and ethnicity, we should also collect a new category of data called granular ethnicity. Granular ethnicity can be described as a person's ancestry, heritage, or cultural affiliation, and it offers minorities an opportunity to identify themselves in their own terms. Examples of granular ethnicity are Haitian, Dominican, Kurdish, Navajo, and so on.

If we apply a granular ethnicity model to the earlier example of our diabetic patients, we could recognize whether foreign born blacks have hemoglobin A1c's that are better or worse than U.S. born blacks and, if so, attempt to target the specific cultural elements that may be influencing this disparity. The streamlined collection of granular ethnicity data through the powerful efficiencies of health information technology will allow us to identify these language and cultural differences that may be influencing our health disparity metrics in ways that we cannot currently recognize. In short, we have important questions that we cannot answer without better data. With the development of the meaningful use criteria, we have a tremendous opportunity to utilize health information technology's capacity to capture, analyze, and share the detailed demographic data that holds so much potential toward the elimination of health disparities.

My recommendations are that meaningful use requirements for 2013 and 2015, number one, adopt the 2009 Institute of Medicine recommendations for the collection of race, ethnicity, and language data. Number two, require regular reporting of quality metrics by race, ethnicity, language, and granular ethnicity. And, number three, that by 2015, providers demonstrate that they are using race, ethnicity, and language stratified quality metrics to target specific groups at highest risk of poor health outcomes with the aim of reducing health disparities. Thank you again for this wonderful opportunity. I also want to quickly thank my advisors and mentors, Dr. Neil Calman, Dr. Patricia Walker from Health Partners in Minnesota, and Dr. Romana Hasnain-Wynia from the Feinberg School of Medicine at Northwestern University.

Neil Calman - Institute for Family Health - President & Cofounder

Thank, Dr. Wilson. We'll now hear from Silas Buchanan.

Silas Buchanan – The Cave Institute – Director of E-Health Initiatives

Thanks very much for having me. I'm honored to be here. I appreciate the invitation. My name is Silas Buchanan, as stated. I'm the director of E-Health Initiatives for The Cave Institute. The Cave Institute is a Bethesda, Maryland, based 501-C3 dedicated to the elimination of racial and ethnic health and healthcare disparities. Our mission is very simple: demystify HIT and inform communities of color and underserved communities about the benefits of adopting and utilizing HIT.

Our strategy is two-fold: to work with HIT application developers to innovate and adapt their products to better represent the wants and needs of communities of color and underserved communities, and also to leverage the trusted leadership of credible, organized, sustained, faith and community-based organizations to engage, educate, and increase the usage of HIT by people in underserved communities and communities of color. Our vision is very straightforward, and that is optimal health for everyone.

Many tools and applications and devices currently are complex and not culturally specific. They are many times intimidating to our targeted patient consumers. We believe that underserved patient consumers are at increased risk of suffering greater disparities in health and healthcare simply because they're not being meaningfully engaged with the current technological shifts. As physicians, hospitals, and other providers are currently being federally incentivized and subsidized to adopt HIT solutions, patients, consumers, particularly underserved patient consumers are often left unaware of the potentially transformative impact that HIT adoption can have on their lives. And when they are made aware, it's not always done in a culturally appropriate way.

So many times it lacks the stickiness that will meaningfully encourage engagement and increase usage. We believe that as billions of dollars are spent to push technology down to providers, we should find a way to elevate consumers and pull them, particularly underserved consumers, up towards technology.

We are concerned about the risks associated with implementing HIT in relationship to potentially increasing disparities, and there are three risks in particular that we focus on. An increased disparity in knowledge about how HIT can improve health outcomes, a risk of further eroding an already fragile trust between healthcare systems and providers in underserved communities, which is real and palatable in our communities. And, importantly, we risk missing the opportunity to have underserved patient consumers participate in the innovation and development of new HIT products, services, and devices. This is also absolutely critical as we go forward. We want to be at the table, at the design stage, not necessary having tools and applications retrofitted for our communities.

As it relates to the possible increase of disparity in knowledge, I am concerned that the pace of innovation and the rate of adoption, adaptation, and usage of HIT by more affluent communities will far outpace the

corresponding rate of adoption, adaptation, and usage of HIT in underserved communities. As it relates to trust, I'm concerned about the lack of understanding around HIT that the leadership of influential organizations in communities of color and underserved communities may have and how that translates to the community itself.

An example of that would be my mom's pastor had a bad experience with his Blackberry, and from the pulpit, holds it up and rails against Blackberry, as well as the carrier. So to this day, my mom will not buy a Blackberry, and she doesn't operate with the carrier that the pastor had. Even though the carrier, she had a fine experience with that carrier, she won't deal with them for that reason. These are some of the realities that we actually deal with from our perspective from a day-to-day basis.

I am most concerned, as I stated earlier, about missing the opportunity to innovate and develop new HIT products, services, and devices with the input of our targeted community. There is no better way to meaningfully engage anyone than to ask their perspective when designing something new. It doesn't matter if it's a house, if it's a new dress for yourselves or for your wife. A natural sense of pride and ownership develops when that solution is birthed. Obviously, I think that would increase usage. So we strongly advocate designing and building Web based applications and tools and trackers for our targeted patient consumers with input from our targeted patient consumers, and then directly promoting usage to our targeted patient consumers with organizations that are aligned with our targeted patient consumers. And so, it just is the IMAPC in Windows 7 was my idea, idea or concept.

One of the things that we're involved in now is framing out a community-based HIT education initiative targeting underserved community members in central New Jersey. We partnered with Meridian Health, which is the largest healthcare provider in central New Jersey, as well as no more clipboard. Their EMR provider happens to be Siemens. No more clipboard is their un-tethered, PHR, patient interface that they are pushing out to the community.

We're also engaged with the partners in health and Latino partners in health in central New Jersey, and they represent a culturally diverse and a very influential subset of national and regional faith-based fraternal community of social organizations and are clearly engrained in the fabric of the community, so they are a key partner. As stated, Meridian currently promotes the usage of this no more clipboard, un-tethered PHR and interface to all of the patients, and is an effective, efficient, and convenient way to engage and interact with their providers and services. But Meridian would like to specifically, as would we, promote the increase in usage of this particular interface by their underserved patient consumers.

We're working with this group to create a culturally appropriate, bilingual, user demo of the no more clipboard patient interface, and the partners in Latino health and partners in health are committed to cracking a community engagement and marketing strategy to reach out to the community and make sure that it's pushed out in a culturally appropriate way.

We're also jointly engaging the libraries and those churches and community centers with technology centers imbedded in them and promoting them as trusted places to utilize this demo. Folks will get trained, and then be asked to complete a brief survey. So our goal, of course, is to leverage the trust and goodwill of this entire consortium to expose, empower, and motivate underserved individuals to use the Meridian Web site generally because we're not getting a lot of hits on that Web site by our target consumers, and specifically the no more clipboard interface.

I mentioned in our written statement our mantra, which can also be used as a hypothesis for some academic study, and that is adoption plus adaptation equals utilization, meaningful use, and disparity reduction, and we absolutely firmly believe that to be the case. As it relates to our thoughts about

meaningful use requirements for 2013 and 2015, we'd like to see the mission and the budget and the strategy actually of the RECs expanded to encourage adoption of HIT by patient consumers and their families, particularly those that are underserved. Assist patients and consumers and their families to become meaningful users of HIT. And increase the probability that patients, consumers, and family adopters of HIT will become meaningful users of technology. These are pretty much the same strategies that have been engaged or specified for providers. They just should be translated to consumers.

The Cave Institute would welcome an opportunity to noodle through and assist in developing specific tactics around those strategies to impact our target communities. We know that great care and budget has been allocated to establish the RECs, and we also understand that the RECs are designed to reach the physicians, but we would like to see some activity through the RECs perhaps. Perhaps some sort of application that can be overlaid on top of the RECs that reaches out to our particular targeted consumers.

Also in my written testimony, I shared an example around a platform, ourhealthministry.com, that we're developing in conjunction with the AME church. It is designed to socially network the church and their 14 connectional health districts worldwide, representative of 6,000 congregations and 6 million people, and tie them all together on a singular platform that disseminates health information and collects data. It is going to embed an electronic personal health record that is avatar assisted as well, and we see this as a prime way to engage communities of color through the trusted purview of the African American church through which many partners can access the community. We know that pharmaceutical companies, health and wellness firms, CPG firms, as well as social services organizations are very, very interested in reaching our community, but haven't found a consistent way to do that. The ourhealthministry.com platform could act as that platform. With that, I'll close and thank you again for the invitation.

Neil Calman - Institute for Family Health - President & Cofounder

Thank you. I think you can see that I was right at the beginning. There's a depth to these issues that those of us who know that they exist, it's hard to appreciate, and each of you in your own area is digging deep into the issues to try to make sure that this technology is rolled out in an effective way. I'll turn it over to you, George, to moderate the questions and answers, or do you want me to do that?

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

You....

Neil Calman - Institute for Family Health - President & Cofounder

Questions from the panel? David Bates.

David Bates - Brigham and Women's Hospital - Chief, Div. Internal Medicine

Thank you for that testimony. I have a couple of sort of questions/comments. The first two go to Sara. One thing that I expected to see, but maybe didn't see as much as I thought I would is recommendations about making it easy and/or workable for surrogates to use PHRs to be able to – especially for the elderly. There are many elderly who are just really not capable of managing things themselves, and it's been kind of complicated to actually set things up so that they work for surrogates.

I also wondered. You mentioned in your testimony the issue of literacy and said that you weren't aware of interventions to address that. Given that, do you think it's important to do research in that area? I do. Literacy is a very big issue nationally. Then a couple of you talked about un-tethered PHRs, and I personally believe we'll get more benefits from tethered PHRs, but I also believe we don't really know. What I would like to see is some more valuations of both tethered and especially un-tethered PHRs to see what the health benefits are. I think that's something that we could work out empirically, and I wonder if you'd be supportive of that.

Neil Calman - Institute for Family Health - President & Cofounder

Sara, do you want to start?

Sara Czaja – University of Miami – Professor

Yes. I think there's another point I want to make that I think is important to make. I think there's an assumption that people have access, Internet access, because there's a lot of data to show that Internet access is dramatically increasing, but I think that if we really pull that data apart, we can see that there are large groups for whom that's not true, such as older adults and minorities and those of lower socioeconomic status. But to get to the point, to get to the point that was raised, we are doing research right now where we're looking specifically at older adults and the use of EMRs and portals, and we're also trying to actively engage with designers of these systems, not only because there are guidelines available that can be applied to design of these systems to make them more usable. Some of them have been generated by our CREATE team, but I think we have a long way to go in terms of understanding of not only can people use them on what are usability problems to barriers, but I also think we need to understand what their perceptions are around the technology. There are big issues and big concerns around trust and privacy that I think needs to be investigated, and I think we don't know much at all about what's the impact on health outcomes. And so I think there are lots of questions beyond usability that we need to start addressing.

Neil Calman - Institute for Family Health - President & Cofounder

Cynthia?

Cynthia Solomon – FollowMe, Inc. – Founder & President

I'd like to just address the issues around tethered and un-tethered PHRs. I think doing some research would be an excellent project. Let me give you an example.

I was in Sonoma County, and in Santa Rosa, there are three hospitals and many doctors, and each hospital has its own EMR system, and each hospital has a patient portal, so conceivably, I could have information at one hospital in my patient portal, other information in another hospital in the portal, and now I have fragmented information electronically. And so the reason that we are pushing un-tethered PHRs that can communicate with the EMRs is so that you have that information in one place. I don't need all the information that's in the hospital record. I just need to know my discharge summary, why I was there, when I was discharged so I can better manage my care. So I think doing a research project would be great, and I'd invite it.

Silas Buchanan – The Cave Institute – Director of E-Health Initiatives

I'd like to add, with the Meridian project, it's about a tethered PHR, frankly, that is run through no more clipboard. What we're doing with the church, however, is around developing our own independent, un-tethered PHR, so there's a tethered PHR through the no more clipboard initiative, and an un-tethered one through our health ministry, and it would be interesting to take a look at the two.

Sara Czaja – University of Miami – Professor

This is Sara again. I agree that that's an important issue, but I really, really firmly believe that we have to start looking at not only the availability of whether – and if it's tethered or un-tethered, but can people use them? Do they understand the information that's on there? And, more importantly, how do they use it? I think we have a long way to go there, especially with the older adult population.

Neil Calman - Institute for Family Health - President & Cofounder

We'll go to Deven.

Deven McGraw – Center for Democracy & Technology – Director

Thank you all very much for this testimony. It's been very interesting. One thing that occurs to me on this tethered versus un-tethered issue is that if we had a portability requirement that allowed you to sort of – whether you're using a tethered, an un-tethered, whether you had both, and you wanted to mingle them, there's a lot to be considered here, and your testimony is really helpful.

I want to ask a question about privacy issues. First, I want to ask you, Cynthia, about the card and what sorts of protections are on the card, say, if you lose it or it gets stolen? We've been hearing increasingly about medical identity theft, and I think sometimes we have to be careful that these simple solutions don't exacerbate what seems to be an increasing problem, so I wonder how you dealt with that.

Cynthia Solomon – FollowMe, Inc. – Founder & President

On the card, I'll actually have a sample I'll pass around in just a moment. It basically has a patient's name. I mean, it is an issue, but I think it's overrun by the issue of, as an example, my son has hydrocephalus and two shunts. So having that card is more – you know, if he loses that card, it doesn't have a social security number. It just has his name, his photo ID, and his condition, his providers, and his allergies. I think that's an issue. I don't see that, I mean, as a parent and a mother, I don't see it as the most important issue. The most important issue for me is the right information at the right time.

As an example in the Health Shack, which is very interesting, a few weeks ago, one of the homeless girls who was pregnant left Sacramento, and I was in another city. She called back to the shelter and told them she fainted, and the paramedics got her card and saw that she was pregnant, and were able to respond appropriately. So I agree it's an issue, but I think it's something we'll have to address as we move along.

Deven McGraw – Center for Democracy & Technology – Director

Yes. Now I don't necessarily disagree with you. I had someone from Louisiana show me a card that they had for their patient portal at LSU, and it literally had a space for people to put their ID and their password right on the card.

Cynthia Solomon – FollowMe, Inc. – Founder & President

No, we don't do that.

Deven McGraw – Center for Democracy & Technology – Director

But when I questioned him about it, he said, well, look. When you're displaced by a hurricane, and you don't know where your records are, worrying about your privacy is the last thing on the list, and so I get that. But I think I'm also interested in exploring solutions that are simple, but still don't leave people exposed. You know, smart cards with chips.

Cynthia Solomon – FollowMe, Inc. – Founder & President

Right.

Deven McGraw – Center for Democracy & Technology – Director

You can turn them on or off if they get stolen.

Cynthia Solomon – FollowMe, Inc. – Founder & President

Yes. I think that's good. We looked at the readers. But the problem is, you have to have a facility to have the reader.

Deven McGraw – Center for Democracy & Technology – Director

Have to have the reader. Yes. There's always something. In terms of the other privacy question that I want to ask of Dr. Wilson, Dr. Buchanan, and Sara on the phone, is about the data collection issues on racial and ethnic disparities, and to what extent are there concerns in those communities about privacy issues with respect to this data collection? And I ask because my sense is that this data gets collected in an aggregate form, so it's not identifiable to an individual, and certainly, given the extent to which these communities are very eager to have this data collected, I don't happen to think personally that there's a privacy issue that needs to be resolved there given, again, that it gets collected in aggregate form.

But there are folks who vehemently disagree with me and think that, for this data collection, you need to get informed consent as individuals before it can be collected. I'm curious, in your working with these populations and what you'd like to see happen in the data collection arena, what your thoughts are on this. Actually, anyone from the panel can address it, but Dr. Wilson, since you made the data collection piece, you know, a centerpiece of your testimony, I'll address it to you first.

Geniene Wilson – Institute for Family Health – Fellow

Right. There have been studies that show that patients, if they understand why the data is being collected, they do want to be asked, and we are actually recommending that when the front office staff asks our patients these questions that this is how it's framed that we want to make sure that all of our patients are receiving high quality care, and that's why these questions are being asked.

These same studies also indicate that patients do not appreciate or feel uneasy if the reason given is that it's a requirement, a federal requirement, or it's some kind of government requirement. Then they feel more uneasy. But if they are told that it's to make sure that it's for high quality care for everyone, then they want to give this information. That research has been done. There are studies that show that. Does that answer your question?

Deven McGraw – Center for Democracy & Technology – Director

Yes. No, it does. Thank you.

Christine Bechtel - National Partnership for Women & Families – VP

I had a similar question, which is ... this is Christine Bechtel. We're delighted that stage one meaningful use does have standardized data collection around race, ethnicity, language, and gender. We would have liked to see us go a step farther and actually use that information in some QA's, including stratifying quality measures, which you talked about by those variables.

The barrier and the challenge that we run into, and I think Deven is raising it, was not only or not just centered around the point at which the data is requested from the patient, but it was also centered around when you – so let's say you stratify quality measures. When you report those measures, even in the aggregate, if you have too few patients in that particular cell, you've got three African American patients who have diabetes in your patient population, that you could end up sort of identifying them de facto anyway.

And I was surprised at the resistance that we encountered among colleagues around this idea of actually stratifying quality measures, so I've been trying to think about a way that we can get the data to be used for exactly that purpose and yet, at the same time, give people some comfort that the point here really is eliminating health disparities. I don't know if you have a reaction to that sort of backend focus of the actual reporting, in our case, to the federal government, you know, what your reaction might be.

Geniene Wilson – Institute for Family Health – Fellow

I kind of find it hard to understand how patients would be identified if you're not using any kind of identifying information, even if it's a small population. I think really those kinds of fears are unfounded, and I haven't read enough about it. I don't know exactly. I haven't seen studies on that in particular, so that would be a good question to look at. Yes.

Sara Czaja – University of Miami – Professor

This is Sara. I know that whenever we do government supported research, we always collect information on race, ethnicity, basic demographic information, which is always reported in our findings and in our results. We have not ever had an issue with people providing us with that kind of information, especially when they understand the purpose of what we're doing, and they always have the option not to provide it. They're always given that choice, but I honestly can say that we really have not had an issue with that.

Neil Calman - Institute for Family Health - President & Cofounder

I just want to make a comment too. I think one of the interesting things about granular ethnicity is that people actually find themselves in the list. It's very hard when you have three categories for people to figure out oftentimes what are they, and where are they. And people feel uncomfortable being lumped, but you find yourself in the list more, you know, if it says Haitian. And I think there's some comfort in that in actually saying the people are really concerned about where I'm from and not just the color of my skin or not trying to lump me into some category.

But I just wanted to respond to one of the things Deven asked too. The purpose of using the information locally is to actually be able to create interventions that help you reduce disparities, so you have to have this stuff and be very connected. And people who are using it to do recall programs or to target particular diabetes groups, to try to bring people together who are culturally similar for nutrition counseling and basically be able to do that stuff is to be able to actually have that data and use it with very specific patient identification information. I think there's a lot to be learned here, but think it's a move in the right direction.

Sara Czaja – University of Miami – Professor

Yes, and let me just echo what Neil said. Particularly in a city like Miami where there are so many different populations, the granularity is in fact very positively received by our population. They don't want to just check that they're black or white or Hispanic. The Cubans want to differentiate themselves as a group, etc. So I agree with Neil on that point.

Neil Calman - Institute for Family Health - President & Cofounder

Sure.

Christine Bechtel - National Partnership for Women & Families – VP

I just want to make a comment about the tethered versus un-tethered thing. I think it doesn't help us to think about an either/or approach. It's got to be both, right? So you're going to have patients who really have a trust relationship with a particular provider and want their information in there. But, frankly, they might like to actually upload information from other providers into that. And they may need to get information out, and one of the things that I'm worried about is that we're going to end up, through meaningful use, unintentionally creating scenarios where patients don't use health information electronically because they have seven or eight different locations where that's stored, and that's seven or eight different user IDs and passwords, and it's too much.

And so I think the flexibility to have every provider's electronic health record have a download capability is going to be enormously important. And I think the other piece of why I believe that is because once we can get the data moving under the patient's control, then I think it opens the door for the private market to

innovate around applications that begin to contextualize the information, make it more meaningful, facilitate online health coaching, a lot of the things we'd like to see providers do in meaningful use, but, frankly, are going to be difficult for providers to do, and I think it'll help us facilitate it in that respect.

Cynthia Solomon – FollowMe, Inc. – Founder & President

I'd love to comment on that. I totally agree, and the technology is there. It's there. It's really, frankly, the bottom line, it's the pushback from the EMR companies that we're having.

Silas Buchanan – The Cave Institute – Director of E-Health Initiatives

Yes.

Cynthia Solomon – FollowMe, Inc. – Founder & President

Imagine your PHR, your un-tethered or, you know, where it can connect to all my doctors wherever I am, and they can download the information. But we're also putting a big burden on the physicians right now who are overwhelmed with technology fatigue. But imagine having a PHR tool, which is available. I mean, it's being created all over the country in which I can have patient education in my language at my literacy level by just pushing a button, recommended by my physician, so you can actually take this technology and partner with your doctor so that he or she can help educate you without taking another two minutes out of their seven-minute visit to figure out the EMR component. I think there's great opportunity, and I would love to continue to advocate for that.

Silas Buchanan – The Cave Institute – Director of E-Health Initiatives

Yes. I just wanted to say I agree with that too. I don't think it's an either/or thing. I do think we need more federal funding for evaluation of these things, and there's almost no federal support for research in this area. Depending on what an individual's situation is, it may be better for them to have a tethered or an un-tethered or both. But there are a whole lot of questions that need to be asked about how to make things work best, how big is the kernel of information that needs to go back and forth, and how do you do the reconciliation when you have medication lists going back and forth and dealing with all the problems that come up? Those issues just really have not been addressed.

Cynthia Solomon – FollowMe, Inc. – Founder & President

I agree. One of the announcements, I guess, is actually Dr. Tiernan is here today. We're working with Children's National Medical Center to create a PHR called Follow My Heart. It's their project. And Dr. Tiernan is the director for managing children with congenital health disease as they transition from pediatric care to adult centered care. You're right. We spent five hours yesterday talking about what needs to happen, what kinds of data we need to ... how that's going to be shared, and I think it is the lack of funding to do this research component that we come up against all the time.

Neil Calman - Institute for Family Health - President & Cofounder

Maybe I could just jump in and just ask you a follow-up question. In terms of the funding, how are the un-tethered PHRs to be funded, and how do you actually see the business model developing? You have 24,000 folks, how is that paid for?

Cynthia Solomon – FollowMe, Inc. – Founder & President

Very good point.

Neil Calman - Institute for Family Health - President & Cofounder

How will it be paid for once people stop seeing this as something that they want to fund with grants?

Cynthia Solomon – FollowMe, Inc. – Founder & President

Actually, after eight years, MiVia is what I would call pretty self-sustainable, and I'll tell you why. Not that it makes lots of money, it does not, because I think the funding is going to have to come from the public sector in one way or another. With MiVia, the payers, you can't join MiVia or even Health Shack unless you go through a provider because, as my colleague back in Sonoma tells me, when you build a car, you can't just hand it to somebody and say, drive it. You have to teach them how to drive it, and that's what we do, and that's what our community partners do, and that's where some of that funding needs to go.

In terms of MiVia, what it does is it's paid for by mostly hospitals and resource organizations. It's actually like a \$3,500 fee to set up with 100 accounts, and then the hospitals, most of our payers are hospitals and resource centers, so it's very low cost, and it actually is able to export CCD and CCR. The problem is getting the cooperation of the EMR companies to be able to share that information, and I have to keep bringing that up because I've been saying it for eight years. Yes, okay.

And in terms of Health Shack, it's just getting launched, but here's a good example. We're working with UC Berkley on the Health Shack project, and with the installation that UC Davis, you know, the research component came in after we installed it, so we don't really know much. It's hard to set up those parameters, and I'm not a scientist, but listening to everyone, I can understand. At the Berkley effort, we want to, we have now involved the county government, residential care facilities, and we're partnering with Berkley on a grant application to actually look at it prospectively in terms of what interventions work. Is it because we use nurses to enroll the kids? Is it because it's peer-to-peer? And we'd like to look at it through the residential, through the country government. That's a big project, but it's hard finding the type of funding to get the research off the ground.

Neil Calman - Institute for Family Health - President & Cofounder

Let me just follow that up because I don't understand. Why would a hospital pay for this?

Cynthia Solomon – FollowMe, Inc. – Founder & President

They are. Actually, most of our – they're paying for it because – let me give you an example: Providence Health System in Oregon. Providence Health System has an EMR within the hospital, but they also have a mobile medical unit. They're also connected to an FQHC, and they have an offsite clinic someplace, so they have a MiVia license. Actually, what MiVia does is it acts sort of like a personal health information exchange, so they can log in, and they can share data between the resource center and between the mobile van and the hospital. Actually, they can connect. If I'm a patient, and I show that all three sites they have my record there immediately, and they can input the information, and I can walk away with it.

Silas Buchanan – The Cave Institute – Director of E-Health Initiatives

I'd like to add something. In our communities, access is still a serious issue, so we're talking about solutions, and we're ... and offering them, perhaps to people who don't even have access to the Internet, and are finding their way, perhaps the library, to access them. But then there are trust issues again that are involved with all of these sorts of things. There are reasons why health outcomes once were a mile radius around Johns Hopkins and Cleveland Clinic are some of the worst in the country. Outreach is not what it should be.

And I happen to live in Cleveland, so I know the folks that manage the outreach for a lot of the health systems there, and a lot of them happen to be blonde haired, blue eyed, white folks trying to go into communities of color, and then they come back. Seriously, and they come back, and they're scratching their heads trying to figure out why these interventions aren't successful. And so there's just some issues, I think, that are more basic that need to be addressed in our particular communities. I mentioned in my remarks that we're not leveraging some of the leaders and communities that we should.

One of the other things that I mentioned is, as we are bringing solutions to the floor, I look at the smart phone, and this is the device that I see as potentially one of the great equalizers around healthcare disparities because most everyone either has one or perhaps could have one. But when you give one to someone that lives in a more affluent area, and we'll say it's the Palm Pre, she has had the Palm Pilot when it first came out. She had the 2.0, 3.0, 4.0, Palm Pre comes out, it's a piece of cake. You want to hand a Palm Pre to somebody who has not had the Pilot, the 1.0, 2.0, 3.0, 4.0, it can be very frustrating and perhaps they'll even throw it down and not utilize it. What could be the great equalizer in mobile technology can also come back to bite us as well, so I just wanted to point that out.

Neil Calman - Institute for Family Health - President & Cofounder

Thank you.

Sara Czaja – University of Miami – Professor

This is Sara. I'd like to echo those points. As I said earlier in our communities with a lot of our populations, they don't have access to the Internet. They don't have computers, and sometimes those who do even have computers don't even have broadband access. So I think that's still an issue to be reckoned with. And with respect to smart phones, I think they do have a lot of potential, but there are populations for whom that's going to be a problem ... as well, such as seniors who didn't grow up with other forms of technology, and also the design of those phones from the simple usability standpoint may be very difficult for those populations.

Neil Calman - Institute for Family Health - President & Cofounder

Thank you. Paul? Charlene, sorry.

Charlene Underwood - Siemens Medical - Director, Gov. & Industry Affairs

Thank you. Charlene Underwood from Siemens, and again, I want to thank you for your testimony. I think the comment is every time we listen to some of the challenges, we really do get humbled with what we're trying to accomplish here. As the policy committee, what we do tends to be big levers, you know, they impact a lot of things, and they have to be rolled out broadly for this to be successful, so I appreciate some of the really concrete recommendations you put in your testimony relative to what we need to do.

But from the vendor community, what we really need to start to foresee is a glide path. So there's a little tension here, probably a lot of tension relative to there's stuff that we've got to figure out because it's got to be researched, yet there's stuff that you'd like to do tomorrow. So we're starting to hear, okay, if you just provide that downward capability, that's going to help a lot. So there are some things that are starting to rise to the top that we see we need to do.

How do we figure out what's next? How do we figure out that glide path, because each of you have represented the disparate needs, the need to deliver in different ways? So do you have any thoughts or input? I mean, clearly getting the data there in granular form to understand what the problem is, is a key one. Addressing it in such a way that you don't have to have access, you can be tethered and un-tethered, so the mobility piece is a key piece of it. But what are your thoughts relative to, given that there's research that has to be done, what that glide path might look like? And if we've got to say, we can't answer that, that's okay too.

Geniene Wilson – Institute for Family Health – Fellow

I just have a quick comment about that. Few organizations right now are collecting quality metrics, period. And even fewer organizations are looking at their quality metrics by race, ethnicity, and language. Clearly that to me seems like the first step towards eliminating health disparities. If you're not looking at them, you're not going to see them, so that seems like a very important meaningful use requirement to

me that could be one of the first steps, and the granularity definitely is important. As we look at this, I think this is an opportunity now to create standards because one of the issues is that the current collection of race and ethnicity data is not standardized, so it's different.

There are more than 80 different bodies that require collection of race and ethnicity, and they have different definitions of what race is. One institution's definition of Asian is different than another institution's definition. So we need standardized definitions, standardized collection of this data so that we can compare, and then we need to look at quality metrics and look at those quality metrics by race, ethnicity, and language.

Cynthia Solomon – FollowMe, Inc. – Founder & President

...focus a little bit on that. I would like to just – I think one way to get there, and I sort of want to partner into what Silas has to say is we already are investing a lot of money in these extension centers, and I would love to see. We're actually, we got a little bit of funding through a grant to establish in September. We're calling it a PHR TA center to work with communities across the country who want to engage in any type of PHR to get the families and the providers involved, but we would love to see some of that money used to provide funding to tie into the extension centers for patient engagement and provider support of patient engagement.

The final comment that I want to make is I ran a health center. I founded a health center for migrant farm workers back in '92, '93. I know how to run a clinic. I know the risks involved and the stresses and the barriers. What I'm concerned about, and I've been watching this, is two things. One is that 24 months from now when the funding, so all these clinics and clinic organizations have gotten all these dollars to establish EMR projects, which are very, very, very expensive.

Twenty-four months from now when those clinics have run out of their grant funding, how are they going to support the sustainability of the technology? Are they going to have to lay off a doctor or a nurse and provide less care because they have to sustain the technology? I think we have to put a little bit of pressure on not adding all. You know, I think the demographic information is critical in that it can be pulled, and that's great, but I think we have to look at the sustainability of IT because I see this money now being diverted into the technology, and I don't want it taken away from the patient care, and we need to really look at that. And I don't know.

Look at how technology companies are building and spending and creating because what I hear from doctors every day is I can't even figure this out. I don't have time to take this class to learn this EMR, and they don't have to. So we have to sort of create incentives and rewards for simplicity, and I think that we can do that with your encouragement.

Sara Czaja – University of Miami – Professor

This is Sara. I'd like to comment in terms of strategies of what we can do now. I think one thing that's really imperative, and I'm talking from a research perspective, and this is one of my recommendations, is that we really have more multidisciplinary team focused kind of efforts where we have the research communities and just looking at maybe some of the quality metrics, developing the quality metrics, evaluating the systems, work closely with clinics, healthcare providers, as well as designers of these systems. I think that we need to really have a lot more forums for those types of interactions.

Silas Buchanan – The Cave Institute – Director of E-Health Initiatives

Yes, I'd also like to add, as we talk about expansion, perhaps of patient and family engagement through RECs, it would be critical to have those actually show up in communities of color. I agree that physician and provider support of patient engagement is critical. It also speaks to increasing the cultural

competency of physicians. We don't see, in communities, a lot of physicians of color, frankly, and we don't see a lot of culturally competent physicians of any color. So any opportunity that we have to actually expand knowledge of patients, families, as well as physicians to make them more culturally competent would be ideal for us, and the REC is a way to do that.

Neil Calman - Institute for Family Health - President & Cofounder

Let's move on to Paul.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Thanks, Neil. I really want to express my appreciation for the panel. I thought it was a very informative discussion and the discussion since then. I just have a couple comments. One is, I totally agree with the need to work with the end users in terms of designing everything from, whether it's the EHR, the PHR, etc., and so I love hearing about the work with the youth without an address, just to avoid ... and the health ministry. It's just a fabulous idea. I will say that, sadly, I don't think there are any disparities in the lack of vendors working with any end user customers, including the blonde hair, blue eyes, not that I would know.

And the second comment is about the granular ethnic data, which I think is so important because we have such an opportunity to work on really one of the main areas, which is the patient engagement and involvement in their own health, and you can't do that without knowing their ethnic background. I remember a program we called personalized healthcare, and it's not the personalize medicine of genomics. It's how do we take into account an individual's ethnic background and their own agenda. I think that's where the big value is.

We aggressively pursue the genomic information, trying to tailor treatments and diagnosis. We have this free information about the granular ethnic background. I think it would be wise for us to spend more time using that data, as you pointed out, Geniune, especially, in tailoring the effectiveness of what we already know from a health science point of view, so thanks for those comments because I think they're right on, and I hope we can take advantage of those.

Neil Calman - Institute for Family Health - President & Cofounder

Thank you, Paul. George?

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Also let me echo, thank you for your work and for your testimony, and for sharing it with us here. That's wonderful. Just first a quick comment, echoing Charlene's comment that there's no difficult problem that can't be solved temporarily by doing research and solving it tomorrow, so we do have to balance doing the research, plus what we can do today, given the frontloading of the meaningful use incentives, so that's understood.

I understand the issue of labeling, and it kind of brings up that there is no one named underserved, and so it's important to lump people together as underserved because that's the only way you get the problem to be important enough that the nation looks at it and tries to solve it. On the other hand, it's a lot of many different problems, and there's a general question of how do you address them all? Is it one set of solutions, or is it 1,000 different solutions?

This is the data collection panel, or part of it is data collection, so how do we check our progress? Is it merely checking healthcare quality, and that covers it, and we just make sure it's good in every group, or do we have to be checking patient, consumer satisfaction, and then if their healthcare is good, but they're unhappy about it because they feel like they're missing out, is that still a failure? Or do we actually have

to check disparities themselves, and even if the quality is good, is there something else we need to measure? So what do we need to measure? And what is our symbol that we've achieved our goal?

Sara Czaja – University of Miami – Professor

This is Sara. I think it's really a multidiscipline – I think it's a multidimensional construct. I think the first thing we have to look at is access, and are there disparities in access? I don't think we've cracked that, not yet. I think patients or populations' perceptions of the quality of their care, their access to their care, their ability to get that care is also an important metric and, of course, the ultimate important metric is, are there disparities in terms of health outcomes? I think satisfaction is an important dimension of that.

Cynthia Solomon – FollowMe, Inc. – Founder & President

Yes, I totally agree with Sara. I mean, ultimately we want to reduce health, eliminate health disparities, and we want better outcomes for minorities. That's our ultimate goal, but I think patient satisfaction is important to look at as well.

Sara Czaja – University of Miami – Professor

Yes, and I think also patient understanding is another issue. I think issues around health literacy are critical, especially when we're looking at trying to empower people to manage their own health.

Neil Calman - Institute for Family Health - President & Cofounder

Yesterday, I was speaking at a colon cancer, regional colon cancer conference on disparities, and they were putting up information on the mortality rate of colon cancer, and they had Asian, black, and Hispanic, and white as the categories, and they were basically showing all of this data, and the data made no sense. Blacks had a much higher mortality, but Latino's were doing better than white, and the Asians were doing better than anybody. And I thought, you know, that might be true of some Asian populations, but not of all. And as they're sitting there trying to talk about this and figure out like how to make some sense out of this data, you realize it's impossible to make sense out of those data because those categories don't make any sense.

I think that some of the graphs that you inserted that you had into your testimony just show how ridiculous it is that we still use these categories many years after we've realized that they're fairly meaningless in terms of understanding the populations that we're dealing with. But I think Paul's point is so critical because this whole issue of patient engagement or ... set of testimonies on patient engagement, trying to engage people where they are and from their culture and in a way that's culturally sensitive, and then lumping people into categories that make no sense to them, let alone to the people that are trying to treat them just seems to be completely out. So I think that should be an area where we should be able to come to some agreement.

But I'm wondering, given that, are there some recommendations that you would make about what categories people should use? Is there a classification system that's moving towards being generally acceptable, one that we could actually come out with a recommendation to say let's use this method to categorize people in terms of granular ethnicity?

Sara Czaja – University of Miami – Professor

Yes. This report from the Institute of Medicine that I've been referring to, in their appendix, they have a list of granular ethnicities. It's a very helpful list in that it has what the Census Bureau currently has, what the state of Massachusetts has for their granular ethnicities. What we're doing for the institute is actually, for the Institute for Family Health, is actually we're using all of the categories, so there's 500+ different categories that we're using for granular ethnicity, and there's also another please specify category, so if someone does not fit into one of those categories, they can also write in their own category, but I think

that the research has already been done. This is a very good place to start is to look at this report carefully and to look at the granular ethnicity list that they have and recommend that that be used.

One thing that this report does recommend is that there's flexibility here in terms of they recommend that clinics and providers look at the census data in their area and provide, use a granular ethnicity list that is appropriate for them, so some areas, you know, 20 granular ethnicities is fine. Some of our clinics in the Bronx that are very diverse, we need as many categories as possible, so it does give flexibility there, but I think the important thing is that if we follow the recommendations in this report, which, like I said, the work has already been done, then we have some very good recommendations and some very good research authority. We have good sound research to base these recommendations on.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

...follow up on that quick. So the 500 whatever, the terms, now that brings back, that would transpose the problems we have as providers of coding against the thousands of ICD-9's. How would we solve that problem? One thing that came up, a thought that came up as you were talking is, I wonder if there is a way to sit down, just like we sit down with people in filling out their advanced directive forms because it's a complicated situation.

But if we could work with folks to pick which of those categories applies to them, thinking about all of the implications. It's not just some of your national background, but it's also your culture that we're trying to get at. Then that could almost be associated with you in some way that's persistent rather than having everyone just fill out a form and picking from 500, which probably is as much as a problem as picking from 4, one could imagine, especially if we want to reuse that information to target treatment or however it is, consent forms, whatever it is that we're going to use it for to make it more effective for you. Have you thought, as a researcher, about this problem of how do we accurately classify folks that we can use that information productively?

Cynthia Solomon – FollowMe, Inc. – Founder & President

Yes. You bring up many points, actually. What we are doing, we have a registration form that I've revised, and it's a write in, so there's not 500 different categories that someone has to circle one of those categories. It just says, please list your granular ethnicity. It briefly describes what granular ethnicity is, and it gives a couple of examples, and then you can write in up to four different ones, and so that's the first part. And we are doing training for all of our staff who is collecting this information on what granular ethnicity is and how to obtain it and how to provide examples to be helpful.

The other point here is that if you have all of these categories, and then you have maybe three patients that are in one category, is that going to be statistically significant in your results? That's something that we're going to look at, as we continue with this work. Most likely the categories that have very few patients in those categories will all get lumped into other, so only the categories that have a large number of patients in them will be significant.

Neil Calman - Institute for Family Health - President & Cofounder

Art?

Art Davidson - Public Health Informatics at Denver Public Health – Director

...presentation. I really appreciate the time that you spent to come here and prepare. I wanted to stick with this idea about granular ethnicity a little more since you said, and I was about to ask, well, how many can you have? And you answered my question with four. So then, how do you analyze? I saw in your graph here that Koreans had a lower rate of something compared to other groups. So if someone had four categories, how would we know that they're in this Korean group? Is it only by having one that you

get categorized, and when I have someone, a parent who is Haitian, and a parent who is Dominican, how do they get lumped or split?

Cynthia Solomon – FollowMe, Inc. – Founder & President

Right. That's another good question. Right now, with race for example, this is just an easier way to think about it. With race, people can choose more than one race. But if you select more than one race, you are going to get lumped into multiracial for reporting purposes. So if someone does select more than one granular ethnicity, they will probably get lumped into multi-ethnic or something right now.

Currently, there's not an easy way to look at that, and that is problematic. One thing that we want to be able to do, and health information technology can help us with this, is that if someone does pick more than one race or more than one granular ethnicity, we want to be able to analyze that also. That's something we're going to have to work towards in the future.

Neil Calman - Institute for Family Health - President & Cofounder

Let me just give another part of that answer, which is, you're talking about the research piece of it. But from a practice point of view, I want to know that the mother is Haitian and that the father is from somewhere. It's trying to identify people in relationship to their culture from a practice point of view. It doesn't matter to me. I don't have to figure out which category they're in. That's kind of the whole problem we've had.

It's sort of, we used this data that we've created so that we can lump people into four lines on a colon cancer prevalence chart, but what we really need to do from a practice point of view in terms of reaching people in a way that's culturally sensitive is to really understand how they identify themselves. I think there's a difference between using the information for research purposes and using it in order to address people in a culturally sensitive way and create interventions that target people who are highest risk. I think those things sort of end up not being the same thing, so in one, you're trying to lump, and in the other, you're celebrating the diversity that comes from really understanding the multicultural aspect of somebody's background.

George? Sorry. Did you want to follow up, Art?

Art Davidson - Public Health Informatics at Denver Public Health – Director

Yes, just to respond. Let's say the parents were Haitian and Korean, and we're looking for an intervention to improve the Korean rates of low, whatever it was, in this chart. Would that push to get the intervention? That was the reason, not so much around research, but....

Neil Calman - Institute for Family Health - President & Cofounder

You would say, you know, you would say to this person, you know, you would identify, and you would ask the question. You'd at least be able to ask the question. You'd say, well, I wonder whether they would be more appropriate to be with a group of Haitians in terms of looking at their nutritional needs or their medication preferences or anything else. And you'd go to that family and ask, but you'd at least have the information to be able to get to that level which we don't have now, and I don't think we have to pick one or the other.

Cynthia Solomon – FollowMe, Inc. – Founder & President

I included in my written testimony some slides from Health Partners in Minnesota. They are doing some work there where they create a patient centered, tailored, preventive services messages that are by race and ethnicity. The example that they give there is for Asian women and breast cancer, a message the provider can read to the patient during the office visit. So you can certainly do things like that with

granular ethnicity, especially if you have a patient population, you know, if you have a lot of certain type of granular ethnicity patient in your panel. But if you had a patient whose mother was Haitian and dad was Korean, you could potentially look at two different messages like that. That's an example of an intervention during a patient visit.

Neil Calman - Institute for Family Health - President & Cofounder

Sara, did you want to say something?

Sara Czaja – University of Miami – Professor

Yes. I was just going to kind of echo what you said. We're currently doing some work right now with Hispanic, Haitian, and African American caregivers. One of the interventions we're doing using health IT is support groups with videophones. We have Haitian support groups, Hispanic, black ... support groups. Because they do have mixed identities, one thing we ask them to join the group that they feel most comfortable with. While we might use the data differently for looking at results from a research perspective in terms of the actual implementation of the intervention, we really allow people choices.

Silas Buchanan – The Cave Institute – Director of E-Health Initiatives

Just to point out that, medically speaking, race and ethnicity of surrogates for genetics and culture, and genetics, as time goes on, we may just measure it. On culture, you may adopt your in-laws' culture for all you know, and you don't pick it up at all. Hopefully, as time goes on, we'll get better, and measure the things we really need.

Sara Czaja – University of Miami – Professor

Right.

Cynthia Solomon – FollowMe, Inc. – Founder & President

Can I comment on that? It's actually arbitrary. Race, there is no genetic. If you look at the genetics, there's really no genetic distinction that classifies races, so the scientific evidence isn't there. These categories are really arbitrary. What's important is the culture and the patient's relationship to the healthcare system and how they interact with their providers, so that's the key.

Silas Buchanan – The Cave Institute – Director of E-Health Initiatives

Right, and race may be an imperfect measure of that culture.

Sara Czaja – University of Miami – Professor

Right.

Silas Buchanan – The Cave Institute – Director of E-Health Initiatives

And maybe we can do better in the future. On measurement, on evaluation, as Neil pointed out, your example with, was it colon cancer and the different groups, and so one of them did well, and so we're done there. And so I think it's important. It's like, we need to do qualitative studies, so I agree on outcomes as number one, but we can't stop there, and I think we need to do qualitative studies and satisfaction studies to see if the answers we're getting, that we're doing so well in this group are in fact true and not just a mistake in measurement or teaching to the test or whatever goes wrong when you do these things.

Neil Calman - Institute for Family Health - President & Cofounder

Paul?

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

I have sort of an out-of-the-box comment in a sense. I thought about this as Neil was talking about the lumping, and in your example of the health partners message about mammography. So ironically, they were explaining how Asian Americans have a lower risk, etc., except when they come here, but we have this Korean blip. So in some sense, I'm wondering if we're trading one stereotype for another. And here's the thought. We're actually trying to use a different marker, granular ethnic data, as another surrogate for what we really want to know, which is, what's your belief system?

I wonder if we should be asking more direct questions about that, and that crosses color and genetics. For example, we would like to understand your belief about medications or about invasive procedures. Religion is another belief system that crosses ethnic backgrounds, but are those more the determinants of what you believe about your health, things that you would like to do, things you're receptive to, things that you're not receptive to, and I wonder if that's what we should be asking instead of yet another clustering technique.

I'm just asking that as an open question because, as we had this discussion, I go, wow. We're doing this. We're splitting them out. Then we're lumping them together. Then we give a tailored best practice message to lump when in fact it just sort of got real confusing when it's really what are you, the individual, all about. And the more we know about you, the individual, the better we're going to be able to help you.

Cynthia Solomon – FollowMe, Inc. – Founder & President

That's a great point. I mean, what we're really looking for, you know, like let's say we find that Koreans have less mammography, well, what are we going to do with that information? We're doing to do some surveys and find out why, right? So you're saying we should just get to the point.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

That's a little bit of my conclusion.

Cynthia Solomon – FollowMe, Inc. – Founder & President

Right, and that's a great question.

Neil Calman - Institute for Family Health - President & Cofounder

I can see Charlene shuttering. The entry history, what do you think about mammography? What do you think about pap tests? What do you think about antidepressants? What do you think about...? But I think you're absolutely right, Paul. We're just kind of taking, you know, we're going from the 50-foot dive to the 100-foot dive, but what we really need to do is get to 1,000 feet. And I think, eventually, we are going to figure out what some of the real critical issues are and people's beliefs.

And I think Silas mentioned trust. That's such a huge issue, just the differentials in the way people trust the healthcare system. I mean, just the things that people come to the healthcare system with and the baggage. And that cuts across all different categories, so you could have somebody who has had great experiences, you know, or I'm thinking somebody whose pastor loved their cell phone, and somebody whose pastor hated their cell phone, and that could mean the difference as to whether or not you accept some messages from your provider that come through your text messaging system. I mean, there are all kinds of things that are going to influence this.

I think you're just trying to dig down to the next level, but it's clearly imperfect. And I think we all sort of recognize that. And I think our timing is out. I just want to say again how much I appreciate the work that you're all doing, not just the fact that you're here today, but the stuff that you're involved in every day is incredible, and I think we will want to stay in touch with you and continue to hear about progress and for

you to share both successes and failures so that we can continue to progress in our own work and thinking, as we come up with recommendations for meaningful use 2013 and 2015. Thanks a lot.

M

Our mantra.

M

Thank you.

W

Thank you.

Neil Calman - Institute for Family Health - President & Cofounder

And we'll ask the next panel to....

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

All right. Thank you. We're going to take a moment for the panel to change. Thank you so much, Neil. Very excellent, and we will be handing it over to Josh Seidman in a moment.

Judy Sparrow – Office of the National Coordinator – Executive Director

...turn it over to George.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Okay, Josh. I'll turn it over to you for the panel on culture.

Josh Seidman – ONC

Yes. Thank you all for coming to testify. I think, as the last half hour suggested, we already have entered the culture discussion, which sort of signifies the challenges that the workgroup had in trying to come up with the ways to break out our day. Clearly many of these issues are interrelated, and so we sort of understand that, as you testify. I think, when we thought about culture, we specifically thought about culture and language, but clearly there are many other issues that would be incorporated into that, and so we sort of leave that to the people testifying to raise the issues about what culture involves.

I also just do want to mention again, George mentioned it at the outset, but this public testimony that is being provided today is part of the input that we are accepting. We also are accepting and encouraging as much input as we can get through our federal advisory committee blog, and I think that is for our last hearing, our patient family engagement hearing, we had more than 50 comments. It was a very rich and insightful discussion that took place there. All of that enters into the public record and helps us, as we move forward, so just encourage that.

With that, I'll now briefly introduce all of the panelists and then ask them to speak, and we'll go in the order from my right to left. First will be Russell Davis. He's the cofounder and president of Summit Health Institute for Research and Education, SHIRE, also representing the National Health IT Collaborative for the Underserved. SHIRE has a mission of elimination of disparities and assurance of universal access to quality-based healthcare and the optimal health status outcomes. He previously was director of a family health center, and has held academic positions as well.

Chris Gibbons is Associate Director of the Johns Hopkins Urban Health Institute and an assistant professor at both Hopkins School of Medicine and Public Health. He is an urban health expert and

informatician, and primarily in the area of consumer health informatics focusing on using health information communication technologies to improve urban healthcare disparities.

Dianna Hasselman is the director of quality and equality at the Center for Healthcare Strategies. She is directing reducing disparities at the practice site project, and she also is leading CHCS's involvement in the allying fight forces for quality initiative.

Deeana Jang is the policy director of the Asian and Pacific Islander American Health Forum. She previously has worked at the center for law and social policy and at HHS's Office of Civil Rights where she worked to insure the health and human services programs are accessible to immigrants with limited English skills under the Civil Rights act.

Wit that, I will turn it over to Russell Davis. Thank you.

Russell Davis – SHIRE – Cofounder & President

Good morning, and thank you for this opportunity. I am, as indicated, Russell Davis, Cofounder and President of Summit Health Institute for Research and Education, a nonprofit advocacy group headquartered in Washington, D.C., but providing services in multiple areas nationwide. I'm also a cofounder of what we call the National HIT Collaborative for the Underserved. And so I am particularly pleased to have this opportunity to discuss what we think is a very important issue.

The issues we are addressing today have been raised by SHIRE before decision-makers and key stakeholders since 2006, and HIT was launched in 2008 in order to increase awareness among a broad cross-section of public, private, and community advocates and leaders. We see that HIT is a tool. It's not a beginning and end, but it is a tool, and we think that if it is appropriately implemented and utilized, we can reduce disparities. On the other hand, we can increase disparities, as have been indicated very eloquently by those speaking before me.

My remarks are based upon the following assumptions: One, HIT can improve the health of consumers regardless of their racial, ethnic, or other demographic characteristics. Benefits include improved personal health monitoring, knowledge and empowerment of consumers and patients, resulting in better preventive and self-management practices. Communications can be enhanced. Increased patient safety can be secured. And there can be a decrease in prescription and medical areas, lower hospitalization rates, etc.

We all know the potential for HIT. I'm pleased to have heard the person from the Roanoke Chowan Community Health Center in North Carolina, and they're reporting a 70% decline in hospitalizations and ER visits and an 80% decrease in total hospital charges following the introduction of the health center's telehealth network. And we can talk more about that later.

As a cautionary note, and this is my part number two, as a cautionary note, however, current evidence indicates that EHR adoption rates among providers servicing communities of color are lower than among other providers. In a study presented in an article that I coauthored with my partner, Ruth Perot, which was published last year by the Joint Center for Political Economic Studies, researchers from the National Center for Health Statistics reported significant differences among groups. They reported in the Journal of Healthcare for the Poor and Underserved, May 2009, that uninsured and underinsured Hispanic and African American patients are more likely than insured white patients to be treated by doctors who do not use EHRs.

Assumption number three, the lack of health IT adoption and use by providers serving the underserved risk to transgression of a key tenant of the hippocratic oath, "Do your patients no harm." We feel that indeed you can harm patients by what you don't do, as well as by what you do. Making HIT available to providers who do not serve these populations without making appropriate efforts to engage providers who do provide care for the underserved will sadly exacerbate health disparities and widen gaps in healthcare delivery and health status outcomes.

Recommendation number one, a prerequisite for making HIT a tool to eliminate health disparities is a robust education and outreach effort targeted to safety net providers and underserved and minority communities with the goal of insuring their ability to make EHR meaningful use criteria to meet EHR meaningful use criteria, and to qualify for incentives provided by CMS.

Assumption number four, it must be stressed that HIT is a tool for attaining parity and quality in healthcare and not a guarantee. In fact, HIT adoption may improve the well being of groups of patients ... all racial and ethnic groups may be improved in terms of their health status. But as Neil has said, and others have said, the disparity between and among these respective groups may remain the same.

Recommendation, it will be important to understand and address the social determinants impacting communities of color and other underserved, as well as to commit to focused interventions, and I emphasize focused interventions, in order to compensate for societal and other factors impacting on minority group progress.

In terms of responses to questions posed by ONC, I would like to suggest this. The first question that you asked was, what do you see as the greatest risks. And we say that the risk ... NHITs here primarily relate to the phased ... implement HIT among vulnerable populations and to provide the technical and financial support systems necessary to facilitate such implementation. Feedback received from community health centers, as well as minority and other "frontline" providers, a majority of whom function in small practices, indicates such concerns as the following: inability to finance the acquisition of EHRs, lack of guidance with respect to making appropriate choices of vendors consistent with meaningful use, unavailable technical support staff to train, loss of staff time, etc.

It's our recommendation that ONC should consider augmenting the outreach and technical assistance capability, as has been mentioned earlier, of regional extension centers, as necessary to address the needs of safety net providers, which, if not faced, will certainly limit EHR adoption and use. What are you and others doing in terms of dealing with the problem? The work of NHIT and SHIRE involves developing a movement to give voices to the voiceless, engaging public, private, and community partners, and putting relationships between HIT and health disparities before key policymakers nationwide.

NHIT has also developed culturally appropriate and geographically targeted strategies for consideration by ONC to force the acquisition, navigation, and qualification of EHRs for meaningful uses by frontline providers. A recommendation is ONC should consider an initiative in collaboration with other federal agencies to identify gray literature ... that is, information that has been identified, but has not yet been published in peer review material.

Question: What research is being done? Well, NHIT has begun the process of identifying the great literature we're talking about, and candidates are being made more aware of what can be done in the field to capture innovative practices. It is my, again, feeling that if we follow some of these recommendations, we can indeed maximize the benefit of NHIT and health information technology. I appreciate this opportunity to speak before you, and look forward to your questions.

Neil Calman - Institute for Family Health - President & Cofounder

Thank you. Chris, please.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

It's my pleasure to once again provide some testimony before this committee. As you know, the subject of healthcare disparities in HIT are ones that I have been focusing on for some time, and I, like many others, believe that NHIT offers significant promise for healthcare improvement. I also believe there is potential for either reduction or increase in one or more healthcare disparities, and I hope my testimony today and answers to your questions will provide some useful guidance, as you develop certification standards for meaningful use. I'll go right to the questions that were posed and start there.

The first question is, what do you see as the greatest risks posed by the implementation of HIT in this area? In my opinion, the greatest risks along these lines is that we develop the field of HIT in general, and the meaningful use certification criteria specifically using a one size fits all perspective. In other words, an under-appreciation of the potential impact of socio-cultural, economic, and environment, human factors issues that they could have on HIT acceptability, usability and, in turn, efficacy of these tools across provider and the patient populations and, therefore, increase rather than reduce disparities would pose a problem.

Another significant risk is that it has the potential to – another risk that has the potential to exacerbate disparities is to take an approach that says the context for HIT in the healthcare system should primarily focus and almost exclusively focus on providers, hospitals, and clinics. As I mentioned in my previous testimony before this committee, the simple fact that we have about 700,000 physicians of which 300,000 are primary care physicians, around 2.6 million nurses, and 5,200 hospitals and clinics versus 356 million patients shows the limitations of that approach, even if we were to be able to accomplish it satisfactorily.

In my opinion, getting patients and consumers connected should go far beyond connecting consumers simply to their health information or to their PCP. It has to be about connecting consumers to whatever resources they need, including providers and hospitals, whenever they need them, to enable them to achieve their health goals. This should not be left to investors and entrepreneurs without professional healthcare training or expertise. Rather, it should be squarely within the domain of a new collaborative healthcare system. This is the health reform that is most needed and is most likely to lead us to the innovations that offer the best promise of health improvement for each health consumer.

It's both gratifying and encouraging to know that the interim final rule for HIT standards implementation specifications and certification criteria for the Medicare and Medicaid EHR incentive program appears to have already taken this into consideration for its proposed stage three implementation beginning in 2015 when it calls for a focus on, among other things, patient access to self-management tools. Implicit in this proposed rule is the belief that patients will, in the future, need and desire direct access to effective electronic tools that facilitate ongoing support for the management of their health and healthcare issues. In addition, it underscores the need for the development of proposed meaningful patient use criteria that work in tandem with the meaningful provider use standards that are currently under development.

The second question, what are you and others with whom you work doing in this area? Well, much of the work that I'm currently involved in is designed to, one, increase awareness of this issue; two, evaluate the potential magnitude and determinants of these issues; three, develop effective strategies and solutions to address these issues. Along these lines, I've published several books, research papers, federal reports, and policy briefs for federal agencies discussing the evidence and implications of several aspects of these issues. Collectively, these and other documents will form the basis of my comments today. If you're interested, and think it would be helpful, I can provide you a list of all those things.

What research is being done or needs to be done in this area to inform the HIT Policy Committee in trying to establish guidelines? Well, in my opinion, the question should not be what can HIT help providers to do to reduce disparities, but rather, what needs to occur to reduce disparities, and is there a role that provider oriented or consumer oriented HIT can play in making these things happen? It's not about the technology. It's about the processes that need to occur, and then can technology help those occur that are not now occurring? Then look to see if one or more technologies can play a role in the identified solution.

There also are some things that we do know. In general, providers have a single patient orientation to practice, yet healthcare disparities are a group or population level phenomenon. I don't have a disparity as an African American black man, but African American men as a whole do in certain areas. As the healthcare system continues to embrace value-based purchasing and reimbursement, providers will increasingly be responsible not just for the patients in front of them, but for all of the patients they see collectively. As such, addressing disparities through HIT will require meaningful use criteria that require the providers' regularly assess their own activities and achievements and adjust their activities in response to what they find with regard to specific disparities' endpoints tailored to the patient populations represented in their panels.

In a similar fashion, meaningful use patient use criteria could possibly be established and tied to both provider reimbursements and perhaps also to other patient benefits. This would then begin to align the incentives between patients and providers along encouraging those activities that would not only improve outcomes, but reduce disparities. In terms of the literature that's out there, this idea that there's a meaningful relationship between cultural factors and technology design actually isn't even new. Way back in the '70s, although it has not been happening in the field of medicine, way back in the '70s, human factors engineers began investigating how cultural factors could influence individual's technology needs. There was a symposium held in 1972 entitled the National and Cultural Variables in Human Factors Engineering, and the documents that emanate from that, there are several of them, which are available, evaluate all kinds of things from legibility of alpha beta characters to working posture to attitudes towards privacy, and explores the implications of these differences for design.

More recently, human factors engineering work also shows that cultural factors influence appropriate mappings between controls and displays, colors and concepts and icons, and concepts. For example, one quick example, while 100% of Americans associate with the concept of stop, don't do something, with the color red, less than 50%, 48.5% of Chinese have the same assumption. So if you involving just simple things as a color of red to indicate the red flag to patients, Chinese individuals may not get that just because the color is red. But if the designers don't know that, and they use the color – you see where I'm going.

Just a couple more – more recent human factors engineering work, large-scale studies in the field of sociology have also articulated differences in how similar technologies are used differently across cultural groups, and I won't go into those, but you could look at that.

In the field of medical informatics, not human factors engineering, but medical informatics, they also have begun to look at this idea of cultural factors and their meaning. In the 1990's, Forsyth articulated the concept of hidden cultural assumptions in health information technology and illustrated that although designers often believe their creations to be culturally neutral, in actuality, technologies embody cultural assumptions that may not always be appropriate for the intended user.

More recently, a white paper by Caplan and Brennan and others emphasized that the next generation of high priority research questions in HIT and medical informatics needs to include investigations about the role of cultural factors. Finally, within academia, there have been beginning work along what is known as culturally informed design. Gustafson at the University of Wisconsin in a chest program has, for example, explored differences in how African Americans and white breast cancer patients used an online discussion group. They found that while African American women use the tool less often than white women, they used it differently. They used it more for instrumental purposes, focusing on issues such as breast cancer treatment instead of social support, which is what the developer was originally suggesting that it be used for.

Subsequent analysis to that, when he started looking at it, he said, well, this may not be related just to technology, but also to cultural assumptions about what we are giving them, so it was a very text-based infrastructure. Well, that's actually known it doesn't work as well in certain minority populations than others, and that may have been reason why the African American patients didn't use it for social support because that's not how we do social support, etc. I think you, again, see the point.

Spanish language, National Library of Medicine site is another example, and we have some manuscripts pending now on how to do this more systematically, this concept of culturally informed design.

In order to fully accomplish this goal, however, it would be important to gain a better understanding of provider and patient knowledge, attitudes, beliefs, preferences, and current practices regarding personal HIT use. This information should then be used in the design of future HIT, which will lead to increased usability, satisfaction, efficacy, and ultimately enhanced outcomes. Because there's a constant evolution of the technologies, as well as personal goals, practices, and preferences, the strategy of assessing providers and consumers and utilizing the information in the developmental process should be iteratively formalized in the meaningful use certification and recertification process. In other words, what I'm saying is, coming up with some standard to say, okay, for CCHIT or others to say, for your tool to be certified, you have to do X, Y, and Z. Well, one of the things that you have to do or may have to do is show that you have assessed both providers and consumers along these lines, certain cultural lines, and use that information in the development of your tool. Then, as for recertification, have you continued to do that and show us where things have changed or the reasons why they haven't changed, because these things could change?

The third question, with patient and family engagement and the care at the forefront of nation's health, what would you recommend as potential meaningful use requirements in 2013? As suggested above and written about in my books and research paper, there are many potential ways. The key point I want to make here is there's no one electronic silver bullet HIT like no magic pill. But rather, the goal should be to encourage the widespread adoption of activities, practices, and processes by both consumers and providers that address one or more determinants of healthcare disparities.

If, one, incentives are aligned through the certification process or through payment or both, for both providers and consumers to engage in disparities reduction activities. If, two, human factors and usability considerations across consumer populations are addressed in the design of HIT for multiple user populations in order to achieve certification. If, three, there are specific focus on disparities measures, as healthcare quality metrics for providers and hospital systems, and perhaps even patients. And finally, four, as more care is driven out of the hospital, into the home and community-based settings, it suggests the need for the development of meaningful use standards for even Allied Health and support services staff such as community health workers and patient navigators and social workers. If these four things are done, they will go a long way towards reducing disparities in healthcare.

How can meaningful use of HIT specifically reduce disparities? Again, many examples could be cited. There are three that I've already given. Providers using their EHR data to evaluate and monitor reductions in specific disparities within their patient panels is one way. Providers encouraging their patients at highest risks for a given disparity to use a consumer health informatics tools such as an online exercise reminder or BMI calculator to assist them, the patients, with managing the issue in question is another way. Or the development of tailored and targeted HIT tools or target populations certified, that's another approach, should some of these tools be certified as certified to be used in a certain population – I'm ending right now. You made me lose my place – so target populations certified, and this could include the disabled, as well as low literate or underserved, or add-on modules for non-tailored HIT provider oriented tools.

Finally, what specific applications have been used? There's no specific applications, and that's not the best approach, I think, to use. In summary, as my testimony suggests, I believe that the best HIT meaningful use disparity reduction strategy is to develop standards that require, one, informed development of appropriate HIT tools; two, requires provider and patient use that focuses on healthcare disparities; and, three, creates mechanisms and opportunities for ambulatory, community-based, patient support staff to meaningfully use HIT to improve specific determinants of healthcare disparities. If the committee takes this course of action, I believe in the future that not only will we have made substantial progress toward the goal of reducing healthcare disparities, but also the work of this committee will be seen as one critical and visionary piece that helped to get us there. Thank you.

Neil Calman - Institute for Family Health - President & Cofounder

Thank you. Dianne Hasselman.

Dianne Hasselman – CHCS – Director of Quality and Equality

Good morning. On behalf of the Center for Health Care Strategies, thank you for this opportunity to speak to the committee and to share our perspective. Very briefly, the Center for Health Care Strategies, or CHCS, is a national, nonprofit, healthcare resource center founded in 1995. Our mission is to improve the healthcare quality and cost effectiveness within Medicaid.

As the nation's largest healthcare purchaser in terms of covered lives, so 60 million and growing very quickly, Medicaid comprises 50+ learning laboratories across the country, laboratories that can leverage tools and resources to reduce disparities in care and transform our healthcare system. We're primarily funded by philanthropies, including the Robert Wood Johnson Foundation, the Commonwealth Fund, and the California Healthcare Foundation. We work with federal policymakers, state Medicaid agencies, health plans servicing Medicaid beneficiaries and, increasingly, providers who primarily serve Medicaid patients.

And so, it's with this perspective of underserved patient populations, state Medicaid agencies, plans, and under-resourced, high volume Medicaid primary care practices that we respond to the committee's questions regarding solutions for using HIT to close or at least not widen the disparities gap in Medicaid. I recognize that time is short. I do want to respond to your questions starting with a few points on the biggest risks that would increase existing disparities.

First, if a state Medicaid agency obviously chooses not to participate in the voluntary EHR provider incentive program or doesn't use the program as an opportunity for greater transformation of the delivery system, the existing disparities gap will widen for Medicaid. The EHR provider incentive program is not just about spreading technology. Rather, it's about leveraging technology to transform the greater delivery system. Most Medicaid agencies recognize this, and many are positioning themselves for greater transformation, but some are not. This divergence in state strategy could threaten to widen

disparities among state Medicaid programs. That said, despite the severe budgetary constraints facing almost every state legislature, we would like to believe that all Medicaid agencies will choose to participate in the meaningful use incentive program.

Assuming that most, if not all, states will participate, the next greatest risk is that of the small, high volume, Medicaid practice, i.e. solo practitioners and practices with three or fewer clinicians. They will be left behind, and that's our concern. We know that small, high volume Medicaid practices serve a large portion of Medicaid beneficiaries, including large clusters of racially and ethnically diverse patients. For example, Michigan Medicaid data show that 50% of beneficiaries in Detroit receive care in practices of three or fewer providers. In many states and regions, these small practices serve the majority of Medicaid beneficiaries, and they are under-resourced and disenfranchised from the larger, integrated systems, and from quality improvement activities.

These small, high volume, Medicaid practices will be left behind if they're not, A, successfully engaged to participate in the incentive program or, B, engaged, but are such a heavy lift for the regional extension centers that they are abandoned. This would contribute to even greater disparities in health outcomes and further disenfranchise ... under-resourced providers from an HIT transformed healthcare delivery system. Medicaid programs can and should help with Medicaid practice transformation activities.

Medicaid programs have been striving to actively engage small, high volume practices in HIT adoption and practice transformation. These efforts have been very challenging for all parties with limited results to date. I've met with solo practitioners in Oklahoma City, Detroit, Philadelphia, and while these physicians truly want to improve care for their communities, they are extremely reluctant to adopt HIT. Many of these providers don't know what a registry is, and they have no idea what HETUS means. Many don't have computers. They are all over-burdened and struggle to lift their heads up from providing basic healthcare services.

That said, the small, high volume Medicaid practices, which do rise to the challenge and implement HIT are empowered by the new patient information they can access at their fingertips. Non-physician staff can proactively identify who their diabetic patients are, what services or tests they have or have not received, and plan accordingly. Medical assistance can assist patients with health education and improve self-care management, address gaps in care, and reduce some of the care burdens that would otherwise be left to the physician.

What are some ideas for addressing these risks? Several state Medicaid agencies and regional quality improvement alliances are exploring viable, effective, and sustainable solutions for engaging and supporting these small Medicaid practices. Through these efforts, which include adoption and meaningful use of HIT, we believe disparities in care can be identified, tracked, and reduced. Examples are to identify and target small, high volume, high opportunity practices.

State Medicaid programs and plans have the ability to identify high volume Medicaid practices or practices on the margin of eligibility. The percentage of diverse patients in those practices and the performance of that practice, with this information, Medicaid and the RECs can strategically target limited resources to these practices, maximizing the bang for their buck.

Two, provide sufficient quality improvement supports at the point of care to augment REC support. Some Medicaid agencies are already deploying quality improvement resources at the point of care. Programs in North Carolina, Oklahoma, Pennsylvania, and Michigan currently deploy quality improvement coaches, pay for and populate HIT tools, share aggregated, practice level performance information with physicians, and provide financial incentives upfront to practices. They recognize that reducing disparities requires

many interventions, not just in EHR. Providing sufficient supports will be particularly critical, as providers move into stage two and quality improvement at the point of care.

Three, leverage HIT for larger delivery system transformation. Medicaid programs need to think about ways to link HIT with medical health home adoption and payment reform efforts. For example, paying primary care practices to be medical homes or leveraging the upcoming increase in Medicaid primary care rates. States like Pennsylvania and Oklahoma are already positioning their programs to do this.

Four, create alignment with public and private payers and purchasers. Under the Robert Wood Johnson Foundation's Aligning Forces for Quality initiative, for instance, regional alliances in Ohio, Washington, Maine, and Minnesota are currently working with their Medicaid agencies to survey high volume, Medicaid practices, and to link specific practice characteristics to clinical outcomes. Understanding these barriers will help – understanding the barriers these practices face will help guide practice-based quality improvement and transformation efforts, including HIT. A number of these regional alliances are RECs or beacon communities.

What research is or needs to be done to help these providers use HIT to reduce disparities? CHCS is currently funding and evaluating two initiatives that I've touched on already briefly on reducing disparities in Medicaid, and those both include HIT, will begin to release findings later this year. That said, more needs to be known about, A, the size and type of these practices serving the majority of Medicaid beneficiaries in specific states and regions including who they are and their resource needs.

How real practice transformation like meaningful use of HIT is sparked and sustained within small, high volume practices. How to make the business case to a small, high volume, Medicaid practice that an EHR will produce a positive return on investment. How to engage Medicaid patients in the medical home and ways that HIT can enhance this engagement. Lastly, the ways that Medicaid and the RECs can successfully work together to support practices in improving quality and reducing inequities.

The committee has asked about strategies and meaningful use requirements that would increase patient and family engagement. There are a few areas. Given the high prevalence of behavioral health conditions in Medicaid, half of Medicaid beneficiaries with disabilities also have a psychiatric illness diagnosis and almost a third of the nation's total mental healthcare costs are financed by Medicaid.

The committee should explore physical and behavioral healthcare coordination measures in future meaningful use requirements. Medicaid patients and their families struggle to address these longstanding silos that exist between physical and behavioral health providers. Similarly, extending technology and meaningful use to incorporate other providers, nursing homes, the long-term care providers, community care teams that are so critical to the Medicaid population will be an important future strategy. Again, the committee can explore coordination measures in these areas.

The committee may also want to explore how the state of Arizona's Medicaid program is engaging its consumers via HIT. Last year, Arizona was implementing Web based e-learning tools tailored to the needs of Medicaid patients and available in the provider offices. You asked a question about how meaningful use of HIT can specifically reduce disparities. I think that's probably a pretty clear response, and I also see I'm already out of time.

Finally, you asked about specific HIT applications that have been used. In our initiatives with small Medicaid practices, they're mostly using a variety of registry applications to address disparities. The other thing that's interesting to note in these practices in particular is that they really feel compelled, or many of them feel compelled to adopt local, homegrown products, as opposed to commercial applications to try to

bring business back into their communities. Unfortunately, these homegrown products often create another layer of complexity, as they are not often readily interoperable.

In conclusion, thank you again for the invitation to participate in this important process and to share our perspective. Our Web site has many resources that might be of value to you: issue briefs, toolkits, and other materials on reducing disparities and care for Medicaid beneficiaries. Thank you very much.

Josh Seidman – ONC

Thank you. Deeana Jang.

Deeana Jang – Asian/Pacific Islander American Health Forum – Policy Director

Thank you, Josh. Good morning. My name is Deeana Jang, and I am a policy director for the Asian & Pacific Islander American Health Forum, and I'm here today representing not only the health forum, but our sister organization, the Association of Asian Pacific Community Health Organizations. Between our two organizations, we work very closely with community health centers and community-based organizations that provide a number of services, including the HIV/AIDS, domestic violence, chronic diseases who have programs that specifically are tailored to conduct outreach and prevention and direct services to our really diverse Asian American, native Hawaiian, and Pacific Islander communities.

We want to thank the workgroup and the policy committee for devoting today's meeting to the critical issue of eliminating health disparities. If I may, because I'm an attorney, I'm going to start with a quote from a prominent legal scholar, John Powell, a prominent legal scholar on race issues. "Policies are designed to be universal, too often fail to acknowledge that different people are situated differently. For racially marginalized populations, particularly those who live in concentrated poverty neighborhoods, there are multiple reinforcing constraints. What is required is a strategy of targeted universalism. This approach recognizes that the needs of marginalized groups must be addressed in a coordinated and effective manner."

And so I want that to be the theme of my points today. We submitted very detailed comments for you, but I want to focus specifically on three issues: data collection, language access, and research. And since the first panel talked a lot about data collection, I just want to make points about that very short. It's really key that data collection on race, ethnicity, and language need is incorporated into HIT products and services. Vendors and suppliers of health information technologies and services must incorporate issues of disparities generally in the design of their products and services. The most obvious example is the capacity to collect standardized, exchangeable data on race, ethnicity, and language need.

Currently, health providers who want to collect this data have to negotiate individually with these vendors and suppliers to customize these products to collect these data at additional costs to them. We fully support the recommendation of the previous speaker, the Institute of Medicine subcommittee on standardized collection of race and ethnicity data for health quality improvement. Recommendations be incorporated and adopted by the ONC and CMS, and issue guidance to the vendors and suppliers to insure that these standardized templates are incorporated into the products and services from the very beginning.

HIT that incorporates this data collection will allow for health quality data to be stratified by race and ethnicity, as pointed out before, but also that these data can be used to provide culturally competent care. The research shows that through greater patient satisfaction, when there's a patient provider concordance in terms of race and culture, and I want to tell Dr. Tang that my 85-year-old mother receives healthcare at his facility, and I was delighted to hear a few years ago when she first started going there

that the physician who was assigned to her was an Asian woman. And I don't know if that was unintentional or intentional or not, but she was very happy with that, and I am very happy with that.

Another important use for collection of data on primary language for patients and family members is to facilitate language access for limited English proficient persons. Given the proposed year one requirement that hospitals and eligible providers document their primary language of 80% of unique patients, hospitals and eligible providers will have robust data about the language needs of their patients. However, if this data is not used to match the patient language needs with competent, bilingual clinicians and/or trained healthcare interpreters, then there's no meaningful use of that health information recorded in the EMR.

Similarly, if the language needs data in the EMR is not used to produce written patient-facing materials such as clinical summaries, discharge instructions, and patient education materials in the primary language of the patient, then all these materials will not be accessible to patients whose primary language is not English. The CMS and ONC regulations requires such patient-facing materials to be made available in a "human readable format". The meaningful use regulations should explicitly require that such patient-facing materials generated from the EMR be understandable by the patient, meaning, in that patient's primary language. The advantage and efficiency of having standardized translations with such patient-facing materials means that such patient provider communication is optimized.

In addition, if the language needs data is not a required component of health information exchange, then effective care coordination is compromised. For example, if electronic prescribing is successfully completed without using the EMR to specifically alert the pharmacist that the patient has a language need, then the opportunity for the pharmacist to be prepared to provide medication counseling or basic drug information or even the prescription bottle container label in the patient's primary language are all missed and less likely to be done when the patient arrives to pick up the medications.

I just wanted to say that when you're looking at the technology for language access, as well as other uses, they haven't been developed together. For example, in the pharmacy example, there are five states that use a tele-pharmacy system where especially patients in isolated areas, rural areas where there may not be a pharmacist in their area, they can get video pharmacy counseling within that. But these systems have been developed. They're not incorporating the fact that there's also use of video medical interpreters, health interpreters that are being used by some of the hospitals throughout the country. Rather than having two separate video systems, why isn't language access incorporated within the tele-pharmacy system?

Just to give an example of something that does work that's provided in the materials, there is a mercury system that's been created by Aloha Care, which is a nonprofit health plan, which, in partnership with Hawaii's community health centers, and they've launched several other innovative initiatives that draw on health information technology to improve the ability to meet the disparate needs of their members. And one such an initiative is to improve their ability to identify patients' healthcare needs, implement effective interventions and better coordinate care with the network providers. Aloha Care has developed an innovative health information technology solution called the Mercury Care Management System, which is currently in its second year of implementation.

In terms of data collection, the Mercury System systematically mines data, including member demographic information, race, ethnicity, age, gender, language, and education, health risk assessment data, administrative claims data, including diagnosis and prescription drugs, and lab results. And the system categorizes members for specific interventions, which include member education to improve compliance with age and conditional specific prevention screening, diagnostic services, and identification

and members for case management services. You can read more about this in the packet, but Mercury also prompts the mailing of in-language educational materials and letters of telephonic member outreach to remind members of appropriate preventive health screenings in the absence of claims data for such services.

The last thing I want to focus on is the gaps in research. In preparation for this testimony, since you're focusing on solutions, I was trying to find practices that work. And, as I said, there's a ... of that information, so our main recommendation is to insure that more resources are devoted to the targeted development of research and evaluation of models to integrate vulnerable populations who have disparities. This is particularly needed, I think, in the area of patient and family engagement. We already see this area that from our organizations we work with that technology has already been helpful. For example, Asian Health Services, as part of their membership meetings where their patients come, they use wireless headsets, which makes it like a mini UN where patients can speak to each other, even though they may speak eight or nine different Asian languages. We've seen this model work in terms of parent engagement for Head Start programs in Washington.

It's especially important to provide resources to evaluate the programs that specifically work and target these populations. These are small, nonprofits. They design the programs to fit and meet the needs of these communities, but there are no resources for them to actually evaluate these programs. I think what we'll learn from the lessons from those programs, we'll be able to design programs that will truly be universal, so there are some good examples from the reach program that's funded by the CDC that actually provides funding to community-based participatory research that addresses specific health areas of health disparities. And I don't know if any of those programs—I didn't have time to look into it—incorporate HIT, but research programs such as that will help inform our process, as we move forward in implementing HIT, so I thank you.

Josh Seidman – ONC

Thank you all very much for that rich testimony. I'll open it up to the workgroup for questions and discussion for our panel. George?

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Two quick questions on meaningful use measures: One of them is, if we take patient education materials and translate them, just address language, and then do they also have to address culture? Now the easy answer is yes, they should address culture. But the problem is, you have to assess feasibility. If we say everything has to be perfect, no one will ever get anywhere. My real question is, do we get, like if you put it into Google Translator and get the thing out, you know, and so at what point is the sweet spot where it's easy enough that people actually do the translation, but that patients will actually understand it and use it.

Deeana Jang – Asian/Pacific Islander American Health Forum – Policy Director

Yes. I think Chris gave one example, but I think the technology for translation is getting better, but it's not quite there. But you're addressing the cultural issue. I was at a forum yesterday where a staff member from CMS talked about when he worked on HIV/AIDS issues, there's a campaign early on when the disease was first discovered where the message was, you are the cure. And the problem was that when you translate that message into different languages, how do you do it, number one? And it doesn't mean the same thing. That means something to specific demographic groups.

I think there are a lot of models in terms of not only, you don't – the best model is to create the materials from the community, starting from their viewpoint, rather than taking the English and just translating it. But other models are, you know, translation, but also getting community input to do focus group testing, have community reviewers to see if it actually translates to what it really means.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Yes. I would agree. I think there are plenty of examples of how not to do it, right?

Deeana Jang – Asian/Pacific Islander American Health Forum – Policy Director

Yes.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

...other places, and there's no quick, simple, easy way to do it either, and it's going to be an iterative process, but what we do know is that it can be done and, increasingly, it can be done at larger scales if we start in the right way. Business is who sell to wide populations have to do deal with this every day, and so they figured it out. Look at the iPad and the iPhone. They figured it out. It doesn't work perfectly for everybody, but it works well enough for most people. And I think it's getting over the hump that this is impossible is the challenge. We just have to start somewhere, and there are things that have been shown. We could talk about them, but it can be done, and we will grow and get better at it as we go forward.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

And the second question, and I guess I'm asking, you know, the audience I'm asking is biased in one direction, but are meaningful use, because you mentioned patient meaningful use and provider meaningful use are measures right now say we have to offer to patients the ability to access their record, a copy of their record, etc. At what point do we measure whether they do it?

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

I see what you're saying. Yes.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

And so the providers are going to be sensitive ... population where they're not going to use it, and now I'm not going to get my incentives.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

Sure. Absolutely.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

On the other hand, if we're going to measure whether they get their heart attacks or not, why not measure whether their patients ... materials?

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

I agree. I would say two things, and I'll let others. Especially in the beginning, I wouldn't suggest or recommend that we have punitive incentives because, first of all, those reasons. But I would strongly recommend that we do have incentives because, one, sometimes it's not happening because we don't recognize we can do something or we don't innovative. We have to innovate all the time for everything, so putting in place some things that would encourage these things to happen is great, and encourage us to monitor them and then go on.

In the beginning, just encouraging them to do them, and then eventually, yes, monitoring the change and the systems. Again, as every provider will tell you and every ... this is not just about the PCP and the use of a technology. It's beyond that, so we have to create in our use principles that sort of environment.

Josh Seidman – ONC

Christine?

Christine Bechtel - National Partnership for Women & Families – VP

Part of what I think we struggle with often is that there are boundaries and limits to what health IT can do and what these meaningful use incentives statutorily were intended to do. As much as I think we all want to use them as a giant lever for health reform, we run into some problems with that. As I think about patient education materials being delivered to patients, it strikes me that there's a lot of educational materials on conditions that exist now that did originate from the communities that were not just sort of translated in English.

Do we have a library of those online that people can, that providers can connect to? And, if not, should we create one? Should the national resource center be one? Does ... have one?

Deeana Jang – Asian/Pacific Islander American Health Forum – Policy Director

Yes. That's something actually we've been advocating for the Department of Health and Human Services. Rather than, you know, force every single provider to create their own materials or get it, there could be a clearinghouse of translated and culturally tested materials that would be great. I think I forgot what it's called. Isn't there some sort of health information Web site on HHS? I think they may have that where people can get health information, and I think that was in Spanish, but for languages that our community speak, there is really a paucity of materials, so there's no great search system for that.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

I would say I agree, and the answer is both yes and no. There's no one clearinghouse, but there are hundreds of millions of places where you can go. But this is an absolute opportunity, I think, where you could – I don't know if it's a policy or a reg, but this specific thing is something that NLM, National Library of Medicine would eat up alive. In fact, they're trying to do it already. So why would we put in place somebody else to try to do this? Partner with them. Suggest them. Help them to do it to develop this thing, which they're already doing, and then the key is educate providers. You have this resource because actually elements of it are already there. It needs to be built out. It needs to be improved, but that's one idea.

Russell Davis – SHIRE – Cofounder & President

One of the things that I would say is this is where the gray area certainly comes into play, and what we are frustrated by, we meaning the National HIT Collaborative for the Underserved, Summit Health Institute for Research and Education, is the difficulty in obtaining funds to actually publicize that great information. A lot of things are happening that are not yet ready for publishing in peer journals. And by the time it's in the peer journal, it's probably.... How do we take advantage of the innovative activities that are taking place at the ground? That is my question to you. I guess it's Ms. Bechtel.

Christine Bechtel - National Partnership for Women & Families – VP

You're asking me?

Russell Davis – SHIRE – Cofounder & President

Yes. As a member of the panel, yes.

Christine Bechtel - National Partnership for Women & Families – VP

I guess I would say two things. One is, I think that's a challenge that we, not we the policy committee, but sort of the universal we struggled with in a lot of areas, and not just this one. It is, you know, difficult to sort of organize and develop and distribute the right information to communities rapidly, but I'm not totally

sure that that's within our purview, so that would be the second thing that I would say, and it might be worth an offline conversation.

Josh Seidman – ONC

Neil?

Neil Calman - Institute for Family Health - President & Cofounder

Just to pick up from where you left off, Deeana, we've been working for a couple of years now to build a link between our electronic health record and the National Library of Medicine where there is an entire library available in English and Spanish, and that link is now available for people who access our electronic health records through the patient portal to be able to click on a problem on their problem list and automatically be brought to the part of the National Library of Medicine that deals with that issue, and so that's the low hanging fruit, and we haven't even gotten there yet.

But the much more difficult problem that we're struggling with is what do we do with things like provider generated patient instructions at the end of a visit? How do we translate simple medical terminology that we've come to sort of use so easily, and we kind of throw these words around, and the words mean something to us, but they don't mean anything to anybody. Even educated, English speaking people don't have a clue what the hell the healthcare system is talking about when they put things in the records.

And as we try to become more and more transparent, I think there's a huge leap that we need to take, and so one of the things that we're doing is January 1st of this year, of this coming year, we're making it basically making all of, taking all abbreviations out of our documentation system, not just looking at what joint commission approved abbreviations are. Basically saying, in preparation for a time when patients are going to be able to access their record, we need to remove abbreviations from the record. That's clearly and, I think, Chris, you mentioned that. That's clearly a barrier.

But then there are a lot of other things that we have to sort of address, and I think they're more difficult, and those are things like just the way we use terms like normal and abnormal or positive and negative, which are so crazy because positive is something people think of as something good. But a positive tuberculosis test isn't so good, and some tests are good when they're negative, and some are good when they're positive. We have to start thinking about terminology. And if we can't do this in English, it puzzles me how we're going to possibly translate these things into other languages where those terms have even other meanings.

I think there's a real piece of work here. I don't know who is going to take this on, but there's a piece of work, which involves actually first just taking the language in which we currently use to describe things in medicine and putting that in simple and more standardized format. I loved your description of what the color red means or whatever. I mean, different colors mean things to people. Different words mean things to people. And so we need to be able to standardize that in some way first so that we can then think about how we're going to translate that to different cultures and different languages.

The two high bars that I think we have to cross are what do we do with patient instructions that are generated like a transitions in care or at the time of an office visit, which is a requirement. And if you have an English speaking provider who basically is using a translator in the office, how do we then generate linguistically appropriate patient instructions that are not – you can't pull off a Web site, but are specific to what you need a patient or what you're recommending a patient to do.

The second is through the patient portals. What do we do with patient portals? How do people access information that's in the electronic health record in English when they primarily speak a different

language? And is there a way to create a patient portal into an electronic health record that translates things or that at least makes some of the information available to them in their own language? I think these are specific areas where if we don't tackle these problems, we have increased disparities, right? The more we depend upon patient portals, printouts for people at transitions of care, health education, all these things that we think are great values. The more we depend upon those things as a way to move towards improving quality, every time we can't figure out how to do that to a linguistically challenged population or – well, challenged to me; it's not challenged to them – but I think we're going to increase disparities, and so that's something we absolutely have to tackle.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

I'd just make a comment on your question. National Library of Medicine may be a place to look, and of all the people ... I think Betsy, Art may know this better than me, but Betsy Humphreys, who I guess is Deputy Director of National Library of Medicine, spent years working on how to get the gray literature encoded for public health, and may be someone who has knowledge and some authority to see how we might address this. That's where I would look, the National Library of Medicine, and Betsy in particular to ask her advice on what to do next.

Josh Seidman – ONC

...respond to Neil?

Dianne Hasselman – CHCS – Director of Quality and Equality

Yes. Those are real challenges. I agree with you. I do want to say that once we answer those questions, I think about how we say it in English first, and then the translation, the technology can help. One example I want to give was from Washington State. They had developed, their Department of Social and Health Services has developed a whole translation and interpreter system. Part of the translation system, which can translate all the notices that go to beneficiaries of social and health services into over 80 different languages, and they've set it up, and they've had to build it on their own is they have a computer that actually stores. Once you've translated the notice, it stores that translation, and they've also developed glossaries in different languages of these social and health human services terms so it's already been tested, and you don't have to worry about translating again and getting a different answer, so that's been really helpful.

And so, because I'm not a doctor, although I have gotten patient instructions, I'm just curious as to whether there are a certain set of standardized instructions that could be translated in advance and tested, and at least stored. And maybe the patient may not get the translation in real time, but if they had a system to send it to a place like the Washington State Department of Social and Human Services, that they could turn it around fairly quickly because these translations have been stored.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

I can offer a few comments there. Let me deal with this one, and then I can do those because they're all related. It illustrates how these things are related and looking at it as just a provider thing or HIT thing is not the way to go, and that all of these things will not come from providers.

There's a group here in Washington, the Center for Information Therapy. And they've been championing these information prescriptions forever, and I thought it was ridiculous years ago, but you know what? I'm changing my mind a little bit. They invited me to speak ... changing my mind.

I mean, what they have been doing and have some expertise, I'm not necessarily saying they're ready for primetime or anything like that, but the point is, they have an infrastructure in place and are looking. They also have an agenda, but again, an infrastructure in place for developing messages that are on the

patient's level about health topics. That's one group and one sort of infrastructure. I'm not saying they're the answer, but I'm saying there are people looking and working along these lines, and we will eventually get there one day, and there may be others that I'm not thinking about or don't know about.

Dianne Hasselman – CHCS – Director of Quality and Equality

Arizona Medicaid....

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

Yes, and that's why I'm sure there are others, and so the committee shouldn't think that all of this has to come from here or from their regs, and I don't know how, if this is even part of your role, but to just say to people, hey, let's find some of these other people like NLM or others. That's sort of one thing.

On the other side of the coin, responding to what Neil was saying, absolutely right. Again, it's not a one size of one approach. It's going to be a spectrum of things that develop over time for that reason, as well as for reasons that minority or low income populations don't have as much technology, as well as a whole bunch of reasons, even before technology was put in place, that there's the movement in healthcare to use or to explore and now efficacy is coming out around all sorts of health workers and navigators and things like that.

One iteration of that is that these individuals bring the technology to people who don't have it in their homes, and there may be some efficacy there, and they will also, could also be the translators or the brokers of that information. That's not an end all for everybody, but it's one way of doing it. Again, I think, as we explore multiple pathways over time, we'll get there, but it's a thorny problem. You're absolutely right.

Josh Seidman – ONC

I guess I'd just ask something that was in Deeana's written testimony that I just wanted to ask you about. I know Chris has done some research on this as well. You talked about the success of wireless and mobile devices, and I'm interested in any experiences that you can share or research that you can share on how those have been deployed in the various populations that you've been discussing and how that can help to address some of the cultural and linguistic challenges.

Russell Davis – SHIRE – Cofounder & President

Here in Washington, D.C., you have eight wards, and we are able to look at each ward in terms of demographics and incidents and prevalence of disease and disability. The worst or the least healthy ward is ward eight here in D.C., and it's also the ward, which has the highest percentage of African American residents, and the lowest per capita income.

Now what an entity out of Howard University is attempting to do because of the diabetes issue in ward eight, they're attempting not necessarily wireless, but moving in that direction to develop a tele-medicine approach to dealing with the gathering and the receipt of information from the patient to navigators and to primary care providers so as to reduce unnecessary emergency room visitations, hospitalizations, etc. And, most important, to identify when persons have not had a foot examination or an eye examination, etc. I think that that demonstration project might have implications for what you're reaching for, for identifying how to deal with the underserved population, particularly when there is the absence of primary care physicians ... in ward eight. Endocrinologists, none in ward eight, so you go and look at these situations. How do you combine technology, if you will, to fill in some of the underserved gaps?

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

Yes. I would agree. From a research perspective, there are a lot of things being tried in a lot of different ways. I wouldn't say any of them are prime time yet either, but there are a lot of things being tried. Again, I say this a lot. I caution that mobile technology is just that. It's just a technology. It's not in and of itself a solution. The question is, what are we doing with it. That could be, that same thing might be delivered over a desktop computer, a cell phone, or a variety of things. But at any rate, so some of the things that I'm aware of that mobile technologies are trying to be employed for, looking at SMS or text based systems to say adolescents, minority, African American, or underserved adolescents at highest risks for HIV/AIDS, which is a particular problem here in D.C.

We know that the activities that put these kids at risk for these things often happen episodically. They go to a party. They do some drugs. They do some stuff, so-called triggers. One idea that's being tried right now is that you give these kids these cell phones that have these buttons on them that are really simple and say, when you, if you recognize yourself to be in a situation that may be compromised at a party or whatever, just press a button, press one of these buttons, and we'll send you a text message to help you avoid your trigger or to potentially get your mind off that trigger and get you to do a different behavior that will put you at lower risk for getting that disease. That's one.

There's just plenty out there and more coming out every day, but which one will really work widespread? I guess I don't know if the question needs to be, which one will work widespread? What needs to be, who are the right people for this right thing, and does it work in that population? As an example, we know that in terms of just getting online by different technologies, African Americans or ... Hispanics, Latinos, far more than any other populations, about 60% of them get online through their phones as opposed to desktop computers or other ways. It's much lower in other populations. So the question is not so much the technology, but who is using it? What's it's most appropriately for?

Josh Seidman – ONC

Neil?

Neil Calman - Institute for Family Health - President & Cofounder

I want to change topics a little bit and just go to Dianne for a minute. You described a situation in Michigan where a huge percentage of the Medicaid population is taken care of in small practices and some concern about their adoption, and I guess I'm wondering two things. One is whether or not you see that group ever being able to adopt certified, meaningful use, capable electronic health records. If not, what the implications of that are.

Two, whether the practices you're looking at are, are people still going into those types of practices? The general sense is those practices are there, but they're kind of like, you know, fading out, and those people are going to all retire, and nobody is doing that stuff anymore, going into a community like that and trying to collect \$25 a visit from folks who are covered by Medicaid, and that they're moving into more institutional or organized practices. I guess I'm trying to understand how nervous we need to be about this. It's clear we need to be nervous today, but do we need to be nervous into the future about it?

And then the second thing, I guess, which is a question for our panelists regarding this, and also for the committee, is what are we going to do to monitor this? If we don't monitor what the impact is of what we're doing on those practices that represent huge percentages of care for the Medicaid population, not even to mention people who are uninsured, how are we going to know whether or not, as we go forward, we haven't – that every day that we're involved in these kinds of incentive programs, we're not just worsening the disparities between the providers and the patients who have access and those that don't?

Dianne Hasselman – CHCS – Director of Quality and Equality

Such great questions, and something that we're really struggling with right now, and that the programs that we're working with are also struggling with that very question, and that is, are they ever going to make it, or should we take our limited resources and focus on other practices, maybe other small practices where there's more of a leadership, a physician champion that clearly sees the benefit of this and that's going to take advantage of this opportunity that's before them. And I guess I'll respond to that.

Some people say, we need to take our limited resources and move on. If they didn't recognize this opportunity, let's come back and visit them in a year. Maybe they'll get it then. But if we look at places like Detroit, Philadelphia, in Arkansas, 80% of the patients there are served by onzies, twozies, these small practices. And so a lot of people say, they're going the way of the dinosaur. Why do we need to invest time and resources in these practices? But they're serving all of these people now, and that's a good question about the future, kind of what is the perspective moving forward? Are there going to be a lot of these small businesses, because that's what they are, or are they going to ultimately be integrated into larger systems?

I don't know if we have an answer for that at this point. We know that there are models out there where systems are trying to reach out and integrate and pull these onzies and twozies into large, more integrated healthcare systems. But we don't know how successful that will be. Has that answered your questions?

Let me put it this way. In terms of do you just abandon them and move on? I don't think we know enough at this point to say that, and I think that the risks are too high, given how many patients they're seeing. They may respond more to a greater intensity of support, or different frequency of support, or different type of support. Some of the practices are saying, hey, don't even talk to me about HIT now. Help me with practice management, and help me just keep my shingle out, and then I can take a breath and get some breathing space and focus more on HIT or quality improvement. It just varies, and we kind of pulling different levers and seeing how best to support these practices. Those are great questions at the heart of this work.

Neil Calman - Institute for Family Health - President & Cofounder

One of the helps that they might get is being helped to integrate into larger delivery systems because it just may not be possible. As you sort of go through this, and we're hearing this, and people sort of going out to practices like that. There are a lot of practices where it is working where people are anxious to do that, and people are out in solo practice, and they're excited, and they see a future in that. But I think, in other places where they're not, it may just not be that the solution is to keep beating people over the head and saying you have to do that. But what I worry about is there are 1,000 patients in that practice, and what does it mean for the future of those 1,000 people whose records are not going to be connected to anything, who are going to show up in a hospital and say, well, but I go to Dr. Jones, and I guess you don't have information from Dr. Jones because they're not on an electronic health record that puts information everywhere.

And just to bring back to the prior panel, this is connected to the tethered, un-tethered PHR question. If you think about what Silas Buchanan was saying before, there's an opportunity for people through un-tethered PHRs to, even if they're attached to a practice that's not EHR enabled, to begin to collect information and put it into a format where it might be sharable with other providers, even if their practice isn't connected. I've heard Chris say this before too that you can't really depend upon the provider-based solutions as your only solution because you have a whole group of providers that are going to be less ready than some of their patients are going to be to take advantage of the benefits of HIT.

Josh Seidman – ONC

Charlene?

Charlene Underwood - Siemens Medical - Director, Gov. & Industry Affairs

Actually, I wanted to add on to the Medicaid area. One of the issues that we face, I think, as an industry is the state variability. And when I listen to some of the Medicaid directors in Pennsylvania and New York talk, each of them are trying to meet their needs of their particular populations, kind of back to what you said, you know, like ... general yet targeted. So we're challenged a little bit because, as we're moving forward with the legislation, and even in the regulations for meaningful use, it said, well, if you meet meaningful use in Medicare, then it should also apply to Medicaid, yet we're not meeting the specific needs of a Medicaid population.

Can you give some thoughts around this balance on states? In your program, I mean, it is sufficient that what we define in these rules – should that be our goal that what we put in our guidance should apply to the Medicare and the Medicaid population? Does there need to be variation? If so, do we have to give guidance at the policy level in this space? I mean, I don't know this answer, and I know, from some of the provider's perspective, having to meet all this variability is a challenge, so any thoughts on that area?

Deeana Jang – Asian/Pacific Islander American Health Forum – Policy Director

Again, a great question. Definitely I think there needs to be some clear alignment between Medicare and Medicaid across meaningful use requirements, or the providers are going to go absolutely nuts. You're exactly right. That said, I think allowing some flexibility – you know, how to do this is the million dollar question around measures that may be really important to a state Medicaid program that are less important to others, that that they really want to focus on and include meaningful use or some flexibility around what types of providers they want to include or focus or try to extend some of their 90/10 funding to help support some of the providers that might be right on the cusp of eligibility or some flexibility in timeframes or when to implement and hit the milestones that are being laid out. I don't know if my answer is very helpful.

Charlene Underwood - Siemens Medical - Director, Gov. & Industry Affairs

Flexibility has been a theme we've heard before.

Josh Seidman – ONC

Art?

Art Davidson - Public Health Informatics at Denver Public Health – Director

Yes. Thanks. Thanks to the panel for the presentation. There was a comment earlier in the last panel from California, the MiVia presentation about sustaining the implementation and making decisions about whether I should keep a doctor or provider versus sustaining the implementation. I thought that that was a challenge for us all.

Josh had the question earlier about what are some telephonic approaches to how we might transform in some ways the care that's provided. I'm interested, Deeana, in your presentation here. You talked about this Mercury Care and telephonic reminders.

Now if I understand this correctly, there's a fairly large Asian population with a variety of languages that are being dealt with there, so I wanted to understand a little more about how that might play out. Chris gave a good example of SMS, and how SMS might be used in those, or is it being used in those Asian populations? How do you work that into the workflow to make an efficient clinic process that may say we don't necessarily need as many providers? We need more of this type of care being provided to that community, because there's this challenge that we heard well from California that I think we all recognize

this is not something that goes in inexpensively. Any comments about that or how that's working for Mercury Care?

Deeana Jang – Asian/Pacific Islander American Health Forum – Policy Director

I'm afraid I'm going to have to get back to you about that because that was the example I was provided by ... and so they're conducting this project. As I said, it's only in the second year of implementation, so I'm afraid I can't answer your question because I don't have the details on that, but I will make sure someone gets back to you about that. I wrote it down.

Art Davidson - Public Health Informatics at Denver Public Health – Director

Thank you.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

I think your point is well taken though. I mean, we can't look at this just as a provider thing because it just won't be solved only as a provider thing. Providers are critically important, but so are a broad range – we have to rethink how we're providing not only what we currently do, but what patients need. Part of that will be through technology. Part of it won't.

Russell Davis – SHIRE – Cofounder & President

Two examples, one from 1978, '79, Kalamazoo, Michigan, community health center, diabetes, uncontrolled diabetes off the rack, uncontrolled hypertension out of sight. We did not ask for more physicians. We asked for more social workers, health educators, nutritionists, exercise persons, recreation persons, and we were able to reduce that significantly. Unfortunately, I don't have the data. I wished I did. But we were able to say, and we were capitated, so we know that our payments per month per patient went down in terms of our paying out to hospitals, emergency rooms, etc. So we did have that.

Here in, again, ward eight, we have an obesity initiative that started off with preschoolers and has now moved to include even geriatric patients. The interesting thing is what we tried to look at is what is the level of readiness to change as opposed to other factors? We found that some of the people were very ready to change. Others were not. Those who were most ready to change ended up becoming peer counselors and navigators. Again, we didn't increase the number of physician services.

But as my paper indicates, and I tried to stay within my five minutes, but you can take a look at it, my background is actually rehabilitation medicine, and another thing that we looked at in terms of rehab medicine was gadgetry, the tolerance for gadgets. Some people have a very high tolerance for gadgets. Some are very low, so you get an amputee, and you provide them with a prosthesis. They may or may not use that prosthesis depending upon their gadget tolerance. And I think the same thing is going to pertain to HIT. If they are afraid of it, if they think it's going to bite them, they're not going to utilize it. On the other hand, once they begin to utilize it, they would become more and more accustomed, and they're going to want.

My mother said I would never drive an automatic transmission. Once she did it, how in the world did I ever live shifting gears, you know? So I think this translates into some of the things, the down to earth things that we would like to talk about through the great literature and other experiences.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

All right. Thank you, Josh. Thank you, panel. That was wonderful. Thank you for all your work. We will be adjourning. Is there any business I need to bring up, Judy? And we'll be adjourning for lunch, and we'll be returning at 1:15 for panel three.

Judy Sparrow – Office of the National Coordinator – Executive Director

Good afternoon, everybody. I think we're ready to begin, if you would please take your seats. Welcome back, and I'll turn it over to George Hripcsak.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Thank you, Judy. Welcome back, everybody, and we're going to begin our third panel on Access. Before I introduce the panel, I just want to point out to our workgroup members, we'll have a slightly modified protocol. We're going to have our first speaker, and then questions, and then our four speakers and questions because of an emergency that just came up. Let me just quickly introduce everybody, and then we'll go through the panel.

First we have Dr. Carolyn Clancy, who is director of the Agency for Healthcare Research and Quality. Dr. Clancy was originally the director for the Center for Outcomes and Effectiveness Research, so very near and dear to the hearts of everyone doing meaningful use, and is also clinical associate professor of the Department of Medicine of George Washington University.

We also have Dr. Howard Hays of the Indian Health Service in HHS. Dr. Hays is a commissioned officer, and he is the investment management for the Indian Health Services electronic health record system, and basically is the one who gets to set the direction on innovation in that area, so it must be a very fun position.

We have Mr. Ian Erlich, President and CEO of the Maniilaq Association and living in Kotzebue, Alaska, 26 miles north of the Arctic Circle, so one of the most northern visitors. Thank you very much for making the trip down here. It's really nice of you to do this, so we very much appreciate it. The association represents 12 federally recognized tribes and he also serves on the Information Services Advisory Committee of the Indian Health Service.

Mr. Scott Hawkins is CIO of Boston Health Care for the Homeless, and they provide comprehensive healthcare for homeless individuals and families. And they've been working on innovative use of HIT for like the last ten years or so any really doing some amazing things there.

And Dr. Cesar Palacios, Executive Director of Proyecto Salud Clinic, which provides high quality, affordable, primary healthcare services to its patients, and have also been working on innovative HIT uses for that population.

Remember that we're asking for five minutes of verbal comments, and we've all read your written comments. Thank you very much for those comments, and I think we'll go right in and begin, Dr. Clancy.

Carolyn Clancy – Agency for Healthcare Research and Quality – Director

Thanks so much. Good afternoon, everyone. You know, as the director of AHRQ, I'm very pleased to be here to offer our perspective on the issue of improving healthcare disparities and how health IT can help address gaps in quality and access to care. Before HITECH was passed, I actually got a call from a consumer group, and I learned about this huge coalition of very diverse groups that had come together to make sure that meaningful use actually included the capacity to collect data on race, ethnicity, and gender. And it was looking at the list, they had an overarching name, but it was quite remarkable.

They said, you have to call up this guy who works in the help community, and I did. I said, I understand you're not onboard with this. And he said, oh no; I'm onboard. I had a question on line 27. Do I need a comma there and all that kind of stuff? Thereupon, he e-mailed me about 12 times, but I think the

important issue is that not only do we get it at AHRQ because it's core to our mission, a broader array of stakeholders actually get how important this is and the size of the opportunity.

We get to see every year when we report to the Congress on how we're doing in quality and disparities, just what the size of that opportunity is, and we've long aspired to try to bring the work in quality and disparities together with health IT, so I'm thrilled that this is on your agenda.

When CHIPRA was signed into law in early 2009, it specifically charts the Secretary of Health and Human Services with the development of a model electronic health record format for kids enrolled in Medicaid and CHIP, so we are doing this through an IAA with CMS, and that's very exciting to us. We're doing it through a subcontract to our national health IT resource center.

My written testimony specifically responds to the questions that you had laid out, so I just wanted to make some additional comments. Children have unique health needs, and their providers have unique data needs. A few years ago, when we thought we could come up with an easy win for doing something right now in patient safety that would make a big difference, it all revolved around being able to link electronic prescribing with weight for kids because that turns out to be a big deal, except that doing it turned out to be a really, really big deal, not let's just call some people up and get this done.

A recent study from pediatrics showed that the EHR adoption rate among pediatricians is about 21%. However, a more thoughtful Academy of Pediatrics survey, only 6% of pediatricians reported having an EHR that includes all the components of a fully functional system. I would love to think that children might be ahead of the curve here or children's providers, but apparently not.

Overall, these records lacked the specification necessary to enable safe quality care for kids, and this is often cited as a barrier by pediatricians. I can't guarantee that if we address those specifications, they wouldn't find other barriers. But nonetheless, mostly I just wanted to say that they have a point.

The model format I mentioned will be disseminated widely to health IT vendors, developers, purchasers, and other appropriate audiences, and the work will help bridge the technology gap that exists for the lack of appropriate electronic tools for health professionals who take care of children.

Now the project is focused on all kids enrolled in Medicaid and CHIP where the greatest disparities exist, but will be actually applicable to any pediatric providers. So our thoughts were that in establishing meaningful use criteria, this committee could make recommendations in areas where we know disparities exist. Because we do an annual report on disparities, two specific areas that are right there are childhood vaccinations and counseling on healthy eating. I'm very pleased that there are going to be two CMS CHIPRA demonstrations that are going to be two CMS CHIPRA demonstrations that will actually evaluate the impact of this model format of the EHR on cost and quality for kids.

Another area that I would hope you would consider is how important it is to encourage patient and family engagement. Obviously it should be patient and family and caregivers perhaps because not all children are living in intact households. One way to do that would be actually to encourage or develop health IT applications that interact with iPhones, phones, etc.

I'm shocked that I don't actually think any of my 20 nieces or nephews actually know how to speak on the phone. Now the youngest is five. He's kind of learning, but it's all text. That is life as we know it, and e-mail them, forget it, you know, weeks later you'll hear. Ironically though, this is not just for kids who have got their own kind of lingo going. It's also for providers, many of whom are walking around with a huge array of clinical information on patients critical to very late breaking sort of urgent decision-making that

never actually ever gets back to the record, and no one seems to have come up with a good answer for that.

Another requirement that you might consider would be that the information made available to patients and families also be available to and easily understood by people who have limited health literacy or for whom English is a second language. We have evidence that health IT can improve health literacy. For example, one of our evidence-based practice centers reported on barriers and drivers of health IT use for the elderly, chronically ill, and underserved found that giving patients online access to a clinician's electronic medical record improves outcomes when combined with tailoring or bidirectional information flow. Research by Adams in Boston also shows that successful implementation of an electronic health record in urban settings was associated with improvements in care.

Work by Dr. Wagner at Uron Hospital has shown that the use of an EHR can effectively improve the quality of care provided to underserved patient populations who traditionally use a hospital's emergency department for their main access point for healthcare. And there's more and more of this going on. We're actually funding a grant, testing something called – testing or evaluating an innovative solution called Parent's Link, a standalone application that runs off any PC and is used to collect information about a kid's symptoms, chronic conditions, medications, and allergies. And for those of you who have children, I do not put, again, all those nieces and nephews, right? There's a whole lot of stuff that doesn't actually all take place at one medical home.

Now we may get to one medical home. That would be lovely. But I think, for the foreseeable future, you can bet the kids are going to be getting, many of them are going to be getting vaccines in one place, advice at schools about healthcare, other stuff from the pediatrician's office, and so forth. I think there's a huge opportunity to take the policy imperative before us and begin to focus both on improving quality and reducing disparities. Thank you very much for your attention. I'd be happy to answer any questions.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Thank you very much, Dr. Clancy. Let me open up for questions initially. I don't want to steal Deven's question, but does the model EHR address the special needs of privacy in children, one of the big stumbling blocks?

Carolyn Clancy – Agency for Healthcare Research and Quality – Director

To the very best of my knowledge, yes. I did not write the scope of work. If it doesn't, it will. How is that?

W

I like that.

Deven McGraw – Center for Democracy & Technology – Director

First of all, thank you for joining us today. The consumer group was the Consumer Partnership for E-Health.

Carolyn Clancy – Agency for Healthcare Research and Quality – Director

Thank you.

Deven McGraw – Center for Democracy & Technology – Director

You're welcome. I shamelessly say that today only because we have a lot of CPH members actually who are here in the audience and have been here, so we're really glad to have them. I want to spring a question on you that actually has nothing to do with your testimony, but I think that you know about and has been bothering me. We heard about it in some of the earlier panels, which is this idea that disparate

populations will experience. They definitely experience healthcare differently, and may experience information technology differently. When I think about patient experience and all the work that AHRQ has supported through CAPs and the development of the CAPs HIT module. I'm struggling to find some ways that we can make sure that meaningful use is actually meaningful to patients and patients of all backgrounds. And so I would love your thoughts on how we might facilitate and what would be appropriate for us to do in the context of meaningful use incentives measuring patient experience broadly, but also specifically with information technology so that we make sure it's really meeting patient's needs.

Carolyn Clancy – Agency for Healthcare Research and Quality – Director

Yes. You know, I often think of the digital divide as being about those young digital natives, all those nieces and nephews, right, and the rest of us poor adults saying, wait a minute. How did you get over there? What's less clear to me is how much we know empirically about do the divides that sometimes related to sociodemographics, do they play out the same way in kids who are growing up with all this stuff or not? Obviously there are children who are coming from very, very poor areas who may not have access to this technology. But between schools and friends, I don't know. I think that's actually something we need to learn, so I think what I would recommend, as this committee follow up with us or my colleagues in the health IT portfolio, and see what we could do, and bring in the folks who work on CAPS.

What I know from a language perspective is, in general, in terms of experiencing healthcare as opposed to health IT, if your first language is Spanish and not English, you will report worse experiences with care. Not terribly surprising given our, how would I say, patchwork approach to translation in linguistic services. But people who are here and whose first language is English, there's no difference at all. So getting to some of those finer grained issues would be helpful. And, finally, I'd just say that it's going to be important to know where the parents of these kids are, so it could be actually that their kids are totally on a level playing field, but there parents aren't even sure what those ... are about.

Neil Calman - Institute for Family Health - President & Cofounder

I guess this isn't so much of a question as a realization from what you said that we're missing some inputs here. I remember that when we were talking about measurement and stuff in looking for measurements for pediatrics, we were all struggling, and this is an obvious connection that we need to make, I would think, immediately is with these folks that are working on this peds oriented EHR. Do you know when that's going to be available?

Carolyn Clancy – Agency for Healthcare Research and Quality – Director

Where did my moral support go? She sat here.

Neil Calman - Institute for Family Health - President & Cofounder

Are there working materials that are available now or anything for people to look at? I think it's obvious that our meaningful use workgroup needs to make a connection with the folks that are working on this peds because one of the things that we've been concerned about is the fact that pediatricians are left out. They're left out in a couple of ways, but they're also left out in that a lot of them aren't eligible for incentive payments because they don't qualify under Medicare. Obviously they don't have a lot of people over 65, and if they don't meet the threshold for Medicaid, they could be taking care of lots of kids, even some Medicaid kids, but still not meet the threshold for being able to get incentive payments, so that's something that we've been concerned about.

Then I guess the other thing that you mentioned was also about school-based providers. We really haven't thought about, you know, there's a growing population of school-based health centers, and we haven't really thought about the integration of how the information in those school-based centers is going

to be integrated into other records that are being collected from other primary care providers, and I think we need to also connect with that issue. Part of what we try to do is to highlight the take home messages from the testimony so that we make sure we don't lose these things, as we sort of move forward, so those are two things that I picked up on.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Paul?

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Thanks, Carolyn. I'm going to pick up on one of your recommendations, just one for measures. One was childhood immunizations, and I think the second one had to do with childhood obesity, correct?

Carolyn Clancy – Agency for Healthcare Research and Quality – Director

Yes, counseling.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Counseling, so the dilemma that we have, at least we face in operating EHRs and PHRs, is this disenfranchised adolescent group. The dilemma arises, so those are clearly folks who want to reach, and these iPhones, etc., is a really good way. The dilemma we have is to be able to give them access, bidirectional access to their records because of the different state laws. As you know, California has about 12 state laws, and how you protect this group, a lot having to do with pregnancy and....

Carolyn Clancy – Agency for Healthcare Research and Quality – Director

And when you become an emancipated minor, yes.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

As a result of that, neither the parents, nor the under-aged minor, can actually conduct this transaction and provide the consent to have this. That creates a horrible gap in our ability to affect this very important group that's going to initiate their health behaviors, their weight, etc. I don't know whether there's any work either that the agency is doing or funding that deals with that.

Carolyn Clancy – Agency for Healthcare Research and Quality – Director

No, but by its important, and just to think about what are the boundaries between EHRs and collecting specifically coded standardized data and social network. I mean, there's a continuum of health information and communications technologies that we link up in all other aspects of our lives, but our legal frameworks and other things have not caught up, so it's something that would be certainly interested in following up with you on or with our colleagues from ONC because I think it's incredibly important. Unfortunately, not many adolescents necessarily make visits for health maintenance exams. In fact, the most common reason for a visit among adolescents is prenatal care.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Thank you very much, doctor.

Carolyn Clancy – Agency for Healthcare Research and Quality – Director

Thank you. Let me just apologize to all of you and thank you for recognizing that, what can I say – I've got people beating on my head. They need stuff right now, so anyway, and thanks for the opportunity to be here.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Thank you.

Neil Calman - Institute for Family Health - President & Cofounder

Thank you very much.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Dr. Hays?

Howard Hays – Indian Health Services – Commissioned Officer

Good afternoon. It's a pleasure to be here. We appreciate the invitation. I'm here in lieu of our CIO, Dr. Theresa Cullen, who was not able to attend, but I appreciate the invitation. My name is Howard Hays. I'm a family physician, and I've been in Indian Health Service for 23 years. I've had the opportunity to serve at several different locations in Indian Health Service. And as George mentioned, I now more or less run the health information system for Indian Health Service, the development and deployment training, that sort of thing.

The Indian Health Service, as you know, the federal agency that serves American Indians and Alaskan natives population across the country, we're in 37 states, and that population by definition has well-known health disparities, and so we do have some experience in that area, and we have some experience using health IT to address those disparities. The testimony that we submitted in response to the questions sort of addresses some of that. I'll try to touch on a few things.

In coming here, I was a little unclear as to the access panel, whether we were talking about access to health IT or access to IT or access to care, and there's actually some overlap in that because, as healthcare becomes more IT dependent, if you don't have the IT access, you don't have the care access. And I think some of the speakers earlier today have addressed that, and you won't hear a lot different from me on that. The providers who serve those populations with disparities in healthcare, typically those providers that are going to have the most barriers to adoption of health IT.

From the standpoint of technology access, in an Indian country, we estimate – actually, more than estimate because we ask this question that, overall, about 22% of our patient population has access to the Internet, and it's much less than that in some areas, and that's traditional Internet access, wired Internet access. The last mile issues are very significant in a widely distributed, rural population, and so some of the things beyond our control is the health agency because we don't run the telcos, and we don't bring those wires out to the communities, and so there's a lot of dependencies on other institutes to bring that technology out to the communities. For part of that reason, I think, is why the handheld and mobile technologies are actually expanding a little bit more rapidly than the wired, Internet technologies, so one of the points that we make is that needing, as I've said, to move in that direction with some of the mobile health technologies and less on the Internet-based sorts of things.

Clearly the ability for safety net technology providers to adopt technologies, there's really not that much money in it for the vendors to try to support all these small facilities and small practices. Obviously the technological competent support in rural areas, I mean, where the tech jobs are not out in little tiny communities, and the availability, I think, the realization that health IT is not general IT. It's very different, and you have to have some clinical expertise to be able to support these, and to implement the business process changes that it takes to implement health IT, and those people just don't exist. If they do exist, they're the smart docs and nurses and pharmacists and stuff that should be seeing patients, and you pull them aside to help them do business process change, and they're not seeing patients anymore, and they don't bring in the dollars. There's this tension between where you're going to get the people to support these, and so I think there has to be a lot of work done in the community colleges and at other levels to really educate this workforce, and with this blended knowledge about technology and healthcare delivery.

From the standpoint of access to care, we've used telehealth extensively, and it needs to grow. I mentioned in-health technologies as well, but the barriers to telehealth and mobile health need to be addressed in terms of things like licensure and reimbursement and medical legal coverage and all those kinds of things. I think a lot of work has been done, but probably a lot more needs to be done in terms of breaking down those barriers to the effective delivery of remote and telehealth driven services.

And as Dr. Clancy mentioned, I think it's really important that not only do our business models of how we deliver care have to change, our whole concepts of what is the medical record may need to change because the medical record no longer belongs in an institution or to an institution. And how do you get that information that takes place over the Internet or through an iPhone or that sort of thing? How does that ever get captured and become part of that patient's comprehensive record because those are important communications that take place.

And one of the mantras that we and my boss, Dr. Cullen, preach are the issues of non-traditional determinants of health that if we're stuck in a medical model of thinking about how health occurs or doesn't occur, then you've failed to address how healthcare should be delivered. To think that the determinants of health status are the same in all communities, the causes of obesity, the causes of suicide, the causes of cardiovascular disease are necessarily the same in the target community, as they are in the dominant community is probably misguided in many cases. And you also can't assume that the community's priorities are the same, that meaningful of healthcare delivery is the same in one community, as it is in the other. And so the bottom line that we'd want to bring is the importance, and that's the reason Ian is here for one thing, but I really hope that this committee and others will continue and strongly engage communities that are receiving these services to help you determine what's meaningful to them.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Thank you very much. Mr. Erlich?

Ian Erlich – Maniilaq Association – President & CEO

Thank you. It's exciting to be here. I realize I wasn't the first choice, as well, and not even the second choice, so I'm just happy to have been able to fill in for the person who wasn't able to fill in for the original person.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Actually, wait. I don't know about that. I think that once we heard your name, you became a first choice. Yes, that was – I was on that call.

Deven McGraw – Center for Democracy & Technology – Director

We got lucky.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

You were way up there.

Ian Erlich – Maniilaq Association – President & CEO

All right. Thank you. Our concern is that with EHR becoming or being mandatory over a time period, which is a good thing, but the problem, I think, that we see is that there's going to be a rush for people or healthcare organizations to implement an electronic health record without taking the time to consider interoperability with other sites, and so it's going to be make the sharing of information, as we move forward, more difficult. We have an example with Alaska where Alaska Native Medical Center is the largest health facility for tribal organizations in the state, and they're moving to a new software system,

which is going to basically make the sharing of information between our facility where we send patients to their facility more difficult, and so this is just one example that we foresee.

The question was also asked that what are you or others ... work or doing to reduce the risk of exacerbating the disparities as HIT is implemented? In Alaska, there is a movement between all the, not just the tribal sites, but also the private healthcare industry to develop a health information exchange, and so we're all participating in this effort, and we think that that's a very significant and important move, as we move forward.

We also think that research should be directed towards analyzing and creating comprehensive statewide health information exchanges in a standard that enables data shares to share data seamlessly between healthcare organizations on a national level regardless of electronic medical record or health record applications and/or software packages. There are ongoing initiatives to develop statewide HIEs. Current developments focus on federal and commercial civilian healthcare providers within each individual state. Development of an interface that would allow data sharing between state HIEs should be researched in an effort to insure patient health information is available when needed regardless of where it's needed.

The fourth question was a real good question, I think, because I think it had a lot of forethought, at least at the HIT committee level that many health organization have, as they're trying to implement something, and that was with patient and family engagement and care at the forefront of our thinking about improving our nation's health. What particular strategies would you recommend as a potential meaningful use requirement?

We think that patient involvement in healthcare is more likely facilitated by the use of an EHR, but currently such access could be limited by whether or not the provider or health center practice chooses to involve the patient. Even when they have an electronic health record, it doesn't necessarily mean that the patient is going to be involved. We think that a requirement could be providing the patient access to viewing their protected health information contained in the EHR while receiving healthcare, for instance, we're suggesting like a second monitor be in the patient exam room, so that as the provider is entering data, it's not necessarily up to them to say, why don't you scoot over here and let's take a look at your record, but that the monitor would just display the patient data and encourage them to – it would facilitate them to be more familiar with what's in their health record and ask questions. We also think that a requirement could be that health facilities install kiosks in the health centers, perhaps to allow the patient to register themselves or to just have a library of health information that they can access at the hospital.

Maniilaq Association, which serves the northwestern area of Alaska with no infrastructure, meaning road systems or fiber connections, has improved healthcare through satellite connectivity between communities and the area. The use of technology in our remote region allows us to provide services from long distances, services such as the electronic health record, tele-psychiatry, tele-dental, telemedicine, tele-pharmacy, and tele-radiology. Video teleconference equipment has also been very helpful from our facility to the villages where the doctors can see the patients real time.

The Universal Services Administrative Company, which provides the funds for us to maintain our circuits, has just made it possible for us to actually do the things that we do with telemedicine and trying to provide access to healthcare in the remote areas. We're really thankful for that, but we also would like to see if it's possible that they could just kind of expand what they're able to fund with their dollars. Our understanding is that they wished they could expand it as well, but they just run the programs, and they keep asking us to think out of the box to see what we could do to take advantage of more of those dollars, but the limitations are pretty rigid, and they're limited right now to more circuits or maintaining the circuits you have. But we would like to be able to access those dollars to perhaps buy equipment, maybe

servers, routers, or even health related technology that we could install to continue making improvements. Thank you.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Very good. Thank you very much. Hawkins?

R. Scott Hawkins – Boston Health Care for the Homeless – CIO

Thanks ... Boston Health Care for the Homeless, where we provide mental health, medical, dental services for homeless adults and families. We create access to care by actually providing care where patients are at. We have 80+ sites, although even for us, sites are determine whether two different park benches are different sites or two different bridges are different sites.

We have teams that go to the wharfs and under bridges, teams that go to motels where families waiting for emergency shelter care come from. We're in soup kitchens and a lot of other places. We also run a 104-bed respite center that provides 24-hour care for those who are too sick to return to shelters or the streets, but not sick enough to require our costly hospital stay. Annually, we serve over 12,000 patients, almost all of whom are below the federal poverty level.

As you mentioned before, we started using electronic health records in 1996. We decided we needed to do that because our patients can show up at any clinic at any time based on what shelter they happened to go in that night, and the only way for us to make sure that care can get there or that their records can get there is electronically. Since then, we continue to add features and functionality to that, as we've seen improve our care, improve the quality of work we do with our patients.

Today we are already using most of the things that are listed under meaningful use. If you're asking me if healthcare technology can increase access and reduce disparities, I think we're showing, with the right environments, you can. I can also say that e-mail and cell phones have definitely improved care as well. Twenty years ago, to reach a patient, you mailed them an item or you called them on their landline phones. Our patients had no landline phones and no physical addresses. Many of our patients have e-mail. A lot of our patients have phones, and I've even seen PDA type phones in our clinics with some of our patients. But that doesn't mean that everything works great.

I can tell you that the meaningful use ARRA dollars to our practice or HITECH dollars are going to continue to improve our efforts, but our biggest and best advancements have always come through collaborations. Our health center controlled network with HRSA funding built our e-referral systems. They built our e-prescribing systems and the health information exchange to which we are participating with. The Massachusetts League of Community Health Centers helped create our quality reporting systems and the Massachusetts Health Data Consortium, which is where vendors, hospitals, for and nonprofit providers come together, and we just discuss what the landscape is like and try to figure out our way through all of this stuff ... expanded our overall knowledge beyond what we could have ever done on our own.

E-prescribing and e-referral have both wide adoption and wide acceptance with providers and patients. They reduce the number of steps necessary to complete care. A patient can now get e-prescribed and then just walk over to a pharmacy and pick it up. A patient can use a referral to colonoscopy. We can make the referral electronically. We can get the dates. We can talk to the patient who already has our trust, and they just need to show up. They don't need to make phone calls. They don't need to try to remember what things to say or what to bring over, and it helps simplify care for them.

Our health information exchange, however, has been problematic and is little utilized, even though we are exchanging continuity of care documents. What we have found is a provider with just a list of continuity of care documents and a date and what site they come from doesn't let them find the last A1c results because they don't know when that test was done. And when you start using this for months, like we have, you suddenly start seeing 50, 100, 200 for a patient. You choose not to go into them, and we're finding many of our providers are just beginning to ignore that feature.

But that said, we still look forward to what this has the potential to do, and we are working with our vendors and others to find a better way of presenting the data. We look forward to more standardization with 2013 and 2015, especially around problem lists and allergies. Even in our 13 center health information exchange and the hospital, reconciling allergy lists and problem lists, we've all come up with our own lists independently is very difficult to do.

Decision support for us is a small part of what we're doing, but it is improving. But even with that, we're beginning to see what we sort of call pop up burnout. When a doctor opens up, a provider opens up a patient record and there are four pop-ups reminding them about their A1c, the hypertension, their pap smear, that they were exposed to TB, that their health insurance is running rate, they forgot to do a copay, they start clicking through them. And so trying to figure out, over all the number one priorities that we should be working on, what are the ones that are really deserving of pop-ups, and how do you present it in the right case.

We are also finding that with the health information exchange that data cleanup becomes an issue every now and then when an inevitable mistake gets made and, four hours later, it's in a health information exchange in a repository at a hospital and shared with 13 other centers, there's not an easy way to say, oops, and try to pull some of that back. And we're still working on that.

And we still have big issues with patient matching. We have an instance in our patient matching system where a patient with a common first name and last name matched on first name, middle initial, last name, social security, and date of birth and does not match in the system because that didn't give it enough weight. It had a different address and a different phone number. For a lot of homeless populations, you're going to have a different address and phone number.

One other point I want to try to make is that the databases are great. You can collect a lot of data with them. But what we're finding also is that our doctors are beginning to start feeling like they're data entry clerks. That with each new state grant, each new federal grant, each new mandate out there, there becomes more data to try to collect. For one Ryan White grant alone, we have to collect 150 different data elements on our patients.

For a patient who is coming in right now for a today issue who doesn't know where they're going to sleep tonight, doesn't know where their next meal is, trying to do education to them on a cancer that might strike 5 or 10 years down the road or a stroke that might happen in 5 or 20 years is very difficult to do. And so our providers regularly find a conflict between our patient centric model of care and the long-term quality goals to which all of us believe are important. And so we don't always get all those measures in the first, second, or third visit because, if a patient thinks that we're wasting their time asking unrelated questions, they just don't come back, and then there is no quality. I thank you for your time, and look forward to questions.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Thank you very much. Dr. Palacios?

Cesar Palacios – Proyecto Salud Clinic – Executive Director

Good afternoon, everyone. It is truly a privilege to be here with you and with this panel. Basically I would like to share a little bit of our experience serving the uninsured ... Montgomery County. Proyecto Salud is one of ten clinics in Montgomery County providing primary care to adults who are uninsured low income in Montgomery County. This year, the safety net is going to serve 25,000 patients and, at the safety net level, close to 70% are Latinos.

Talking specifically about Proyecto Salud, close to 90% of our patients are Latinos, mainly from Central America, South America, and the other 10% are patients coming from originally from Asian and African countries. We mainly serve immigrants. For that reason, of course, we try to be culturally and linguistically appropriate or competent in the services that we provide. Most of our staff is bilingual due to the majority of our patients are Latinos, of course, we have a lot of Latinos in our staff. Of course, we have two or three providers that can speak in Mandarin or French, Portuguese.

Some of the things that I highlighted in my testimony, in my humble opinion, there are a couple of things that we have to take into consideration if we see the health IT can provide all the benefits that, in theory, can provide. We see it in two parts. One, in aspects that could be barriers or challenges for our patients, and some other aspects that have to do with the medical providers and how we work to overcome those barriers.

I wanted to mention first of all the risks that I see in our group of patients because they can go young, while we at the clinical level could do if we don't take into consideration of those things because there are some social and economic components. We serve mainly, as I mentioned, immigrants, regardless of ability to pay or legal status. We do that because we think it's the right thing to do. We think that there are implications in public health, and we know that if we don't become the medical home of this individual, they're going to end up in the emergency rooms. Anyway, all of us are going to end up paying for that care because we pay taxes. For that reason, the first part that I mentioned concerning our patients has to do with health literacy level, computer literacy level, and of course, English language proficiency level.

Many of our patients, of course, to survive in this country, you have to speak English a little bit, depending on the job. But talking about healthcare is so complex that our patients would prefer to speak their problems, health problems in Spanish. Of course, thinking about how to analyze the recommendations of the doctor have to be in Spanish as well, even though they could understand the words. Getting the impact and, you know, I know most of you speak other languages. You know that there are fine differences between things, you cannot get them if you don't speak the language of the patient. So we see that thing.

On top of it, not just the health literacy level and computer literacy level, which talks about the technology gap. We think about also the level of education where our patients in general, even in Spanish, what is the level in elementary school, so there are a lot of barriers that we have to think about how to tackle these. How can we have our patients taking advantage of these types of technology? Many of them don't have access to computers, but has been said several times even at this meeting.

And most of them have cell phones. They don't have landlines. They are a mobile community. They are poor, and maybe they're living in a house with several other people, and they move when they have to move. So that's why they use the cell phones. We should think about using that technology to send this type of message and to take advantage of technology.

We have been working in a quality improvement initiative for the last 18 months, and we were lucky to secure some funding from foundations. And we've been working how to gather enough information data

in our EMR system. The name of this EMR system is CHL Care, which is community helping, which is not a full-fledged EMR system. And, every year, we get updates, you know, upgrades. We can do a little more things depending on how we realize that we have this need to know something to adopt something else, so it's been a long process, and I'm allowed to tell you that we have some progress concerning getting lab work uploaded into the record of the patient.

We have a connection with the referral system, which is another big challenge because we provide only primary care. But there are other ... networks that provide pro bono specialty services, but it's not enough. There's a long waiting list, but with technology, we connect the specialist with the primary care doctor, and we get the reports, so we have access to that ... we are very sort of ... also the connection. We're working on the connection of our clinic with two emergency departments of two hospitals in the county because we would like to not just become the medical home of those that go frequently to the ER, but also if some of our patients, you know, they go to the clinic, but we don't know that they went to the ER because they don't say it, or they don't say that they went.... If we are connected with that, we have seen that all the ten clinics have access to the record of this patient. Of course, there are some other challenges because if they give a slightly different name, there are going to be two records, so there are a lot of challenges that we see along the implementation of these things.

The last thing that was mentioned is about connecting the ER in the clinics to become the medical home. Of course, we would like all of our patients to use the ID cards, so they can use them when they go to the ER, and the doctor at the ER can get the e-chart of the patient. This is the big component that all the providers could have access at this point. Of course, it needs to be upgraded and really get to work in a safety net way with the specialists, with the hospitals, and the other clinics that the patients move. That thinking about how the patients could have access to this information is not just that the patients are going to be reading the record.

I'm sure I'm not saying anything new. Maybe it might be some ... repeating some things, saying that if the patients can read something, that's good, even if it's in Spanish. But if the patient cannot understand what is being said by the doctor or the team, we don't get that much. Even if we have all the resources to establish the safety net connected with the IT resources, if the patient is not engaged on this, we can get just so far in this work. I would say, again, in my humble opinion, that disparities are going to be. Why there? Because of it, because those with higher level of education, no barrier with languages, better understanding of how the system works are going to take better advantage of this good thing that can come from the implementation of IT. And those that don't have the language capability, don't have computers, cannot understand what the doctor is saying. They're going to be left behind, so that's a huge risk that I see.

Of course, I would think about strengthening health education, trying to facilitate the understanding of the patient. Trying to facilitate how the patient can use this information that we can provide to them. It's not just going to be how easy is it for them to access that. I've been proposing about having computers in the waiting room area. That's great. We can have access. They can have access to some Web sites.

But there's got to be somebody acting as a cultural broker to, in a way, help the patient assimilate all the flow of information that they're going to give because almost anybody can get into the Internet now, but how can they choose really what information is worth seeing, reading, and applying. There's got to be somebody helping them, and that's one of my proposals. There's got to be for the real application of these new technologies in getting the patient engaged and also getting the family engaged in this process. There's got a facilitation on how they can use this information.

Of course, I know that at some other level, there's some concern about patients having their own information because it could be used against the provider, against the system. But I would say, in the good way our patients, the patients in general need this information to really participate in ... what the doctor is proposing, why he or she is proposing that, in getting to some agreement about it. Something that I can tell ... patients, this is one of the main decisions that we have to take care with our patients at the clinic. There are a lot of myths and misunderstandings about the use of insulin.

Many of them think that using – many you've heard about this. Many of them think that if they start with the insulin ... basically they can get blind, and we know that it's not true ... year they have been suffering the disease. But there's got to be somebody really helping them understand this, showing that we have been able to show how they have controlled their hemoglobin A1c and other process indicators for helping them to understand what is the impact of their behavior in diet, exercise, and taking their medications, or if there's a need for a more aggressive treatment in taking into consideration what the doctor is saying, not just listening to the provider and doing ... you have to do, not taking into consideration that there is a need for mediation, somebody to really facilitate ... otherwise my perception is, no matter how good technology gets, especially in connecting the whole system, hospitals, you know, shelters, clinics, specialists, it doesn't matter. We are going to get to a point, at least those of those that are serving the really low income, uninsured. In this franchise, we're going to have a big limitation about getting their indicators, their outcomes improved.

They're going to improve. We have seen improvement in our patients concerning hemoglobin A1c over the last 18 months because of the changes in the flow of the clinical sessions and some specific actions that we know that those changes, those improvements are going to have limitations if we don't take into consideration other variables such as really strengthening how they understand this information. Thank you.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Thank you very much, panel. We really appreciate it. That's a wonderful job. We're going to be opening it for questions now. I can start with, so something triggered in Mr. Erlich's presentation about the second monitor and not having it so the doctor is inviting you into his or her world, but it's the patient's world to start with. You need the second monitor, so the patient feels like it's their world that the doctor is being invited to and not the other way around, and it kind of triggered the thought of expectations and maybe to what degree does teaching every population, underserved or not underserved, to have expectations of what HIT and healthcare should be doing for them and have them poll the doctor to do this technology, and so the second monitor being one example that you could trigger that thought, but what are your thoughts about that? Like getting to it not just through monetary incentives, but increasing these populations' expectations of what we should be offering them – how to do it or whether that's part of it. So the homeless, you know, here's what you need to know. If you're going to see a doctor, teaching them here's what your doctor should be doing. They should be using a computer.

Howard Hays – Indian Health Services – Commissioned Officer

Right.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Did they look up the thing on the computer? Did they enter your data? Did they ask you what your race is? Did they ask you your ethnicity?

Howard Hays – Indian Health Services – Commissioned Officer

We at least started with trying to work on pap smears by bringing the nurses in more, so our nurses do triage when a patient first arrives, and the nurses have spent a little bit more saying, you know, your

doctor should be asking you about, you know, getting your pap done because that's going to really help your care. And even just that little nudge from the nurse, we've had more patients ... the nurse told me I have to be getting this done soon. When can we get that scheduled? Not, obviously, universal adoption of that, but that we have more patients who are asking for it.

I have theorized, but not gotten anyone to buy into yet that actually the triage sheet, when we're done, we should give to the patient to hold onto to bring to the doctor, and have the patient see the little list that says when the last A1c was done or what test results are in and out of range, and what that might do for the patient when they interact with the provider. I can also say that my last employer at Catholic Charities ... Mental Health Provider when we started doing laptops in mental healthcare when the providers were really worried it was a barrier. But when they found that they sat next to the provider filling out family history and ... that the patient voice just flowed through ten times better, and that even some of our more paranoid patients were much more at ease when they could see exactly what was being typed in the system. And so it actually went. It was not a barrier. It was actually, it helped care in many cases.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Again, to you, what kind of devices are you using when you're out in the field, and how do those devices communicate with your record system?

Howard Hays – Indian Health Services – Commissioned Officer

We use basically a variety of laptops and air cards, the size of laptops, the security, size, or durability of the laptop up to the provider, so we've used, not pushing any vendor, but Panasonic Tough Books that can take sort of the pounding and still do well, but those are heavy, and so some providers want small, light, NetBooks that they can have places. But we have providers who open up their little NetBook and air card, even on Boston Commons, and can pull up through a Web portal, pull up our electronic health record, see the patient's full record, and e-prescribe directly through that. Generally, anything that leaves our building is hard driveless so that....

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

...I'm sorry...?

Howard Hays – Indian Health Services – Commissioned Officer

Doesn't have a hard drive. There's no way to save any data locally, and it saves us from having to figure out all the encryption and other pieces like that if there's just no way to save any data locally. There's no patient data on any of those devices.

Ian Erlich – Maniilaq Association – President & CEO

George, sorry if I don't understand your question, but we're actually, since we thought of this idea in preparing the testimony, we said at our facility, we've got to put our money where our mouth is, and so we're ordering the second monitors, and so we're hoping to use them right away. But we also think that over a short period of time that the expectation would be on the patient that if they do go into an exam room and see a provider, and after having the experience of seeing their health record one time, if it's absent the next time, they're going to ask for it, and so that's just kind of what we've....

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Yes, I would love that....

Neil Calman - Institute for Family Health - President & Cofounder

So when they're looking at their monitors, they're watching the doctors write all these abbreviations and all this shorthand stuff and all this medical jargon and all the stuff that's completely meaningless to them.

So what are you doing on the other side of that? Are the providers being trained to document differently? Once you open it up to the patients, there's a responsibility on the providers to document in a language that patients can understand. I mean, in English even, in a language that patients can understand. Otherwise they're just looking at garbled stuff on the screen.

Howard Hays – Indian Health Services – Commissioned Officer

I think you have to understand that it's a new idea, but I think that what it inevitably going to do is make those patients ask questions. What does that mean? Some will, and some won't. Some patients that we deal with may not.

Neil Calman - Institute for Family Health - President & Cofounder

We don't have to wait for them to be begging for us to translate these things.

Howard Hays – Indian Health Services – Commissioned Officer

No.

Neil Calman - Institute for Family Health - President & Cofounder

I guess my point is, there are two things that seem to have to happen simultaneously. One is to make this accessible, but the other is to immediately think about what kind of training needs to go on the provider, so they document in a way that when the patients are looking at the screen, it makes sense to them.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

I'll just point out that our patient engagement hearing last month, we talked about needing to get data to patients now. And so you're doing it right now, like it's showing in the screen as you do it, so that's a good first, that's great. Christine?

Christine Bechtel - National Partnership for Women & Families – VP

This is Christine Bechtel, and thank you all for being here today and traveling here. Every panel today has talked about mobile devices, and it's an area I'm intensely interested in. There are a couple of really interesting pilots, I think, across the country that are using mobile technology in different ways, and it's the one technology that at least today seems to be used by a pretty broad swath of the population, more so, I think, than home computers.

As I think about, I want to ask a two-part question. The first is, how do you envision mobile phones being used in this regard in terms specifically of the interaction between the care team and the patient? So there are lots of mobile apps that we can use to manage our own health information, but the context is meaningful use, right? And, under the law, the incentives go to the doc and all the other hospitals, etc. My question is, how can we kind of creatively use mobile applications and then, kind of working backwards from there, what's the pathway that we do? What do we do now? What do we recommend that ONC and CMS do first in 2013 to start to stimulate providers to be able to do this, to want to do this?

I could think about, it could be provider to patient, but it could be provider-to-provider so that you know, because you've got a text message from the hospital that said Christine Bechtel was here last night, FYI. Okay. Now I know to get the record. I'm just thinking simple, but something that is powerful so that we can start getting patients and providers talking to each other through these devices, and then how do we build that into meaningful use?

Howard Hays – Indian Health Services – Commissioned Officer

I think it's a really good question to which I do not have an answer because we are in fact constrained ... what this whole group is by the law, which is meaningful use of electronic health record technology and this kind of went to what I said a while ago is the meaning of the electronic record, the meaning of the record, the traditional meaning of the record that is kept in a doctor's office or hospital of the care that's delivered, but that the technologies that we're talking about go way beyond that.

My belief is that in how health has to support the communication where the doctor can either, through this technology, advise the patient. Your results are back. Please call me or even disclose the results, which is a little trickier when you don't actually know who is on the other end of the phone. And the patient can also ask questions. My sugar is 215, and do you have any thoughts? That kind of stuff, and that communication probably wouldn't go to the doctor. It might go to a diabetes educator, that kind of thing. But it's not part of the record.

So within the constraints of the HITECH Act, I don't know. Maybe I'm too short-sided myself, not knowing quite how to engage the ... health possibilities because they're really not part of the electronic health record, unless you're actually perhaps generating those messages from the EHR and receiving them in the EHR and archiving them.

Christine Bechtel - National Partnership for Women & Families – VP

...I'm sorry in advance. There'll be another one coming later.

W

(Inaudible.)

Christine Bechtel - National Partnership for Women & Families – VP

Which is, what we're already thinking about reminders going, you know, for followup care or preventive care, and our recommendation didn't stipulate how that would occur. And obviously it would be based on the information that comes from the EHR, but not necessarily flowing directly from the record. So I'm thinking about kind of what are the basic building blocks of getting the care team to be able to use this technology so that we can then start to ask the vendor community, here comes the heart attack, to build this capacity on a standardized basis into certified electronic health records.

W

Can I ask? I want to add on. May I ask? A lot of what you talked about was collaboration, and there's collaboration software out there. Are you using any collaboration? Not that I want to create any more strokes here, but it strikes me that if we're going to move into 2013, 2015, we want to get to care management kinds of software, and it's going to evolve over time, so you have experience with those kinds of software in your environments at all, or do you have desires for that kind of capability?

Ian Erlich – Maniilaq Association – President & CEO

Not at our center.

Howard Hays – Indian Health Services – Commissioned Officer

You mean in the course of delivering care?

W

Yes, or the outreach. You do a lot of outreach to your communities, again, coordinating with different, either caregivers or organizations.

Howard Hays – Indian Health Services – Commissioned Officer

We clearly do a lot of outreach, but at this point we're not using technologies that are associated with the electronic records. We can do group visits using the electronic system, but that group is there, physically there, and it's documented in sort of the traditional way. It's just, you can have a whole group of people documented. But to broaden that out to, can we have a virtual group visit, you know, that's a possibility. But I haven't really taken it there yet.

Cesar Palacios – Proyecto Salud Clinic – Executive Director

I want to say something, and maybe going to the previous question, something about what you say about working as a team, clinical team, and I see that as a key component to this. One experience that we have is concerning the diabetes school, guiding the patient to develop or formulate a self-management goal, whatever they decide, walking 30 minutes 5 days a week or something like that.

But anyway, that information can be placed into the future care, and all the team members, we did that from the person doing the intake, asking the person, hey. How are you doing? How was your walking, etc.? And then go into the exam room, and the provider, because sometimes the providers in the past didn't pay that much attention to the health education component and the self-management team. But when the doctor said, when the doctor asked a specific question to the patient about her weight, it brought to her attention that it was important for the doctor. It was important for the person taking the intake, and everybody knew about what she had proposed, the patient.

We saw a really good change, more awareness of the patient that we were working as a team, and ... had access to the information is what they proposed. It raised a little bit the commitment that the patient had about his or her own, you know, self-management goal. Something that you mentioned about the use of the cell phones, of course the simple thing could be the reminders, could be recording specific messages with the ... with the specific provider.

We have different providers. All of them have different personalities. Some of them could be more strict and more direct about specific advice. We have one nurse practitioner. She's really good. But some of the other team members say, you know, she was talking to clear about some things to the patient, but about if you don't do this, you're going to have this, and this, and this consequence and this type of thing. And to my surprise says one of the providers that many more patients want to be seen by her. It's like she makes the connection. If she would record a message, a health message, you know, for the patient to receive on the cell phone, I would say that the patient is going to pay attention.

W

Yes.

Cesar Palacios – Proyecto Salud Clinic – Executive Director

And, also, at the safety net level, we have a referral line that anybody can call to the referral line and ask for questions, appointments, or whatever. If this patient could have access to the information or the patient because it's Web based, if there are specific questions that could be easily answered just by reading the chart without other components that the provider should be included could be provided to the patient at that point.

When you were asking about how the interaction of the provider with the patient with this texting and this type of communication, I see difficulty with our providers in our experience because we have to work a little bit more in quality improvement and development of the panels, so patients that still we end up with the provider having a huge panel of patients, and how this provider is going to be really responding to this.

I would think ... how to respond to this as a team, as a team, and somebody from the team having access to the provider that usually has less time because ... busy, busy, busy all the time, somebody is at the lower level, if we can call it the lower level, can resolve an issue of the patient. The patient is going to feel that he's being attended by the clinic, by the team. He's going to get responses. And if it's something more complex needed, you know, the team is going to have access to the doctors to be able to respond. But ... providers, I see a problem with that, even with some providers. I see difficulty really adopting this new technology, so it's another issue that I mentioned before about workflow.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Neil?

Neil Calman - Institute for Family Health - President & Cofounder

Just so we don't feel like the three panels are totally disconnected, I wanted to have a chance to ask you a question related to one of the earlier panels, and that is about whether or not you all capture at the point of registration information about preferred language, race, ethnicity in your systems, and whether you've looked at any kind of outcome measures by that, and whether it's been helpful. Specifically, I'm thinking about, since we were talking about granular capture, whether or not within the Indian Health Service, people capture the information about, I don't even know what the proper term would be, tribes or regions or whatever they do, and whether or not you all look at differences in outcomes and structure, any kind of interventions based upon that information that you get.

Howard Hays – Indian Health Services – Commissioned Officer

Good question, and it's interesting that you ask that question and that this has been such a focus today because, in the last few days, we've had a lot of discussion about that internally because of the meaningful use requirements for capture of race, ethnicity, and preferred language. We have always captured tribal affiliation because we're the Indian Health Center, and there are 565 tribes or whatever that we deal with, so we capture that.

Now I cannot say that we have taken that data and then matched that up against health outcomes or health risks or that sort of thing. That may have been done. And clearly it's not been done, I don't think, from our system. It's clearly been done. There's been very clear data established that what used to be called the Pima Indians were the highest risk for diabetes, and smoking didn't occur on the Navajo, but it certainly occurs in the Plaines, and those risks are associated with that, so there clearly is a lot of information, but not necessarily directly derived from our information system.

I was very interested to hear today about how much real passion there is about getting this race and ethnicity data when, in our system, actually there's some pushback to asking the race question because we're all Indian. Why are we here? Why are you asking me this question? There's actually some history about the relationship between the federal government and the tribes that people are really sensitive to the race question.

We're having discussions even today about whether to require that race be a question to ask at registration. And the other question is whether it's appropriate for the registration clerk to be asking that question, and whether that's more of a clinical question. Should the nurse intake person when they come into the clinic? This is a question that has to do with their medical risks, and doesn't have anything to do with their insurance or anything like that. Why are we putting that in the registration and not at the point of care or interaction with the medical team?

Neil Calman - Institute for Family Health - President & Cofounder

So it would seem like....

Howard Hays – Indian Health Services – Commissioned Officer

So just to finish, we've always captured tribe. We have some HRSA funded clinics that because of those grants, they have to have the race, ethnicity, homeless, migrant worker kinds of questions asked, and we've built those in, but now we're doing some refinement of that for meaningful use and actually changing the parameters about whether it's required or not to ask those questions in order because our customers want to meet meaningful use, and if they don't get this certain percentage of patients with these questions asked, they're not going to get meaningful use.

Neil Calman - Institute for Family Health - President & Cofounder

I'm thinking about it from a policy point of view that in terms of resource allocation, another reason to do this is around resource allocation, so you wouldn't want to send a whole bunch of diabetes educators to a place that has a very low prevalence of diabetes, but you'd probably want to send a lot more of them to a place that has a high prevalence, and I'm thinking like if we're collecting this data, I guess one of the fears I have is we're going to be collecting this stuff, and nobody is going to look at it, and it's just going to be more information. And so, you know, I'm trying to stimulate some thinking about how do we actually take the information and, if you have all this tribal information, and try to begin to look at resource allocation, but also to anybody else on the panel if you've looked at this in any way yet.

Ian Erlich – Maniilaq Association – President & CEO

We've actually not been able to capture race and ethnicity in our electronic health records in our practice management system, and so it's just captured over there, and we've found a way to send it over, so at least a provider can see the information, but it has been a struggle. And when we do our annual UDS reports, trying to get the two databases to talk to each other to pull that out takes us work every year. We're working on a project right now actually that will integrate our practice management and our EHR together, which will be completed the October/November timeframe.

Cesar Palacios – Proyecto Salud Clinic – Executive Director

We also collect racial and ethnic data, something we have seen because the majority are Latinos that they tend not to identify race when they're supposed to provide that information. That's something interesting. Maybe they don't fit into black or white because these are the ... but it's something that we have to work on that, so ... because we know ... black, white, Haitian, Latinos.

R. Scott Hawkins – Boston Health Care for the Homeless – CIO

One of those issues we've had with those questions is trying to identify where the standard, you know, what's the standard code set that you're supposed to be using for those kinds of things? We've struggled a bit with that, being asked to collect certain data, and wanting to know what data should we be collecting here because it hasn't yet been standardized in some of those areas. And so we just kind of cast a ballot for who has done what and see what seems to fit best. And so it would help if recommendations or requirements for meaningful use ... came along with, you know, we know we have to use ICD-10 or SNOMED or something like that. But when it comes to some of these funkier, less clarified things, I'd be nice to know what they're actually looking for because we also are kind of a vendor of a medical record because we make it, and we have to get it certified, and we have to know what they're going to be testing against. And even reading the NIST test is leaving us a lot of questions on that.

Right now, on ethnicity, we have no granularity at all. It's Hispanic or non-Hispanic, so I was very interested to hear that comment this morning about the ILM report and actually e-mailed some people. Would you look at this and see if this is going to help us at all?

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Great ... all these crazy questions. So the people at this panel are special, in a sense. It tends to be, we see the people. We invite the people who are ahead of the pack and have, you know, it tends to be people who are leading an organization. They have leadership skills. They tend to be after the grants. Then you have your friends, either across the state or down the block. Dr. Hays, you see a broad array of people, and so then there are these other people who are serving underserved populations who don't have quite the same leadership skills or haven't gotten those grants. Can we, through meaningful use, reach out to them, or is it only going to be the few who are really unusual and able to, you know? Is there anything special we have to do? Are there underserved – are there underserved providers, in effect?

Howard Hays – Indian Health Services – Commissioned Officer

I think there clearly are underserved providers. I think they were described earlier today. They're out there just trying to keep their heads above water just making ends meet. Part of the reason I'm in the Indian Health Service is when I got out of medical school with the National Health Service Core Grant, I could either go into private practice in an underserved area and try to make it, or I could go into Indian Health Service where there was a structure there, and I made the right choice. I wouldn't want to be in that other situation trying to run a business of medicine and trying to figure out how to implement HIT and get a few extra thousand dollars out of it.

M

...EMR.

Howard Hays – Indian Health Services – Commissioned Officer

The answer is, yes, there are.

Ian Erlich – Maniilaq Association – President & CEO

Right, so in our 13 health centers in our, what is it, health center controlled network, I was told to pound that into my head several times before coming here. I think the last ones are just getting their EHRs now, and so there are, even in our own little group, sort of early adopters and followers. But for the followers, I mean, for them, it's taking a little bit less money, and a little bit less effort because there are a lot fewer unknowns. And so they're dragged along, but they're dragged along by their peers, and they have people to turn to, but they are eventually coming along as well.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

That's good news, you feel like community health center number 14 came along, you could handle it, and you could help them through it.

Ian Erlich – Maniilaq Association – President & CEO

Yes. The health center, yes, the health center controlled network can handle it. I don't know if I could ... and they have that. And even with 14, they couldn't do all 14 of us at once on any one project anyway. That would overwhelm anything, and so it is several years to get all the way through all those pieces. Now that means I do worry about the ones that are further behind when it comes to meaningful use. But then again, I'm still worried about us because sometimes changing a ship that's already out there is more difficult than building one from scratch. We've built a lot of very bad habits since 1996 within electronic health records, and have had to adjust practices as we go.

R. Scott Hawkins – Boston Health Care for the Homeless – CIO

I think one of the points that he just made that I want to expand on is because meaningful use came out as starting in 2011 and ending in 2015, everybody thinks, at least the people that I work with, we suddenly have to get started on doing this by 2011. And, in our experience, you can't go from zero to meaningful use in a year. It takes a while. It takes a long time to do the business process changes and

implement the pieces of the record that will bring you to that. I keep coming back to them saying, no. Meaningful use starts in 2011, but you can actually start in 2012, 2013, and you can still get your incentives, but they want the incentives next year. And so there is a risk to a precipitous implementation that will actually fail ultimately, and so I think it's well intended that there's a – by 2015, we want everybody to meaningful use, and there are stages in between. If you start later, you've got to move faster, but there is what we're saying in our population, kind of we promoted it because we wanted to say we're going to have an EHR out there that you can use for meaningful use, so they all think they can adopt it, and it takes a long time to get there. And so I know where I'm going except the perception may be that I've got to do meaningful use in 2011 to get my incentives.

I kind of wish – I'm glad the Medicaid incentives go to 2021. The Medicare incentives are shorter. I'd like to see them be able to start later and go and still get their five years in without having to feel like they have to start next year.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

And I heard you earlier about the rushed too, that it may ... like a balloon. You push here, it comes out there. So you push meaningful use, but then you lose some HIE in your example. Other questions?

Art Davidson - Public Health Informatics at Denver Public Health – Director

I have a question. One thing, I'm just not entirely clear, just to even start my question is, so the IHS runs clinics. Is that right? Or they fund other providers who give service to Native Americans?

Howard Hays – Indian Health Services – Commissioned Officer

All of the above. The Indian Health Services federal agency funded through interior through HHS, but we have – if you count all the facilities up in Indian country, it's about 600. About 120 or so of those are run directly by the federal government. We've got about 30 hospitals and about 60 health stations or health centers, which are about 40 hours a week, and health stations, which are less than that, funded directly by the federal government, and that's about half.

The total service population is about 1.9 million, so bigger than a small state, but spread out through 35, 36 states. And about half the population is served directly by the federal government in these facilities run by the federal government. About half of the funding goes to tribes who run their own programs: hospitals, clinics, and mostly smaller clinics and, in Alaska, 160 village clinics, which don't even have – it's a completely different model. It's a great model, but it's a different model, so most of the facilities are actually run by tribal programs.

And we spend about a billion dollars a year buying services from the private sector. If you're at a hospital that doesn't do gall bladders, or if you're a clinic, and you don't have a hospital, and you send the patient into the hospital, that's – we're also a payer to the private sector for those services.

Art Davidson - Public Health Informatics at Denver Public Health – Director

So the half that are cared for in the 120 clinics, if I heard ... or facilities, are using, as I understand in your testimony, the....

Howard Hays – Indian Health Services – Commissioned Officer

RPMS....

Art Davidson - Public Health Informatics at Denver Public Health – Director

...taxpayer developed software, which is the VA system, right?

Howard Hays – Indian Health Services – Commissioned Officer

It is. The IHS system, RPMS and the VA system kind of grew up together, so you might as well say they're using our system. But all the federal programs around RPMS, and about 95% of the tribal programs also run RPMS.

Art Davidson - Public Health Informatics at Denver Public Health – Director

That would answer my question about how many were actually using the same system. Now a tribal member moves from one clinic to another, it gets back to something Dr. Palacios brought up about multiple records. How does IHS deal with that? And maybe after that, I could ask you to describe how that works in Boston as well. You know, when people move from one place to the other, I just want to understand how serious a problem that is in terms of record dispersion.

Howard Hays – Indian Health Services – Commissioned Officer

I think we're on the cusp of that changing, but the IHS system is a locally implemented system, so local client server, so each facility has their own database, and we do have a mobile population, whether it's snowbirds or people traveling a lot, and so there is an issue with records in multiple places. But using the interoperability standards in the Nationwide Health Information Network, we're basically, this year, on the verge of launching that ability to do direct views. We won't be integrating the records necessarily, but through CCDs, and I really appreciated the comment about the CCDs because I agree with that. But through the CCDs and the HIEs, we'll be able to look at that much more....

Art Davidson - Public Health Informatics at Denver Public Health – Director

But how do you resolve when someone, just as Dr Palacios described, comes in with one name, and then a slight variation the next point, and then ... identity established?

Howard Hays – Indian Health Services – Commissioned Officer

We're using a mass person index, an MPI.

Art Davidson - Public Health Informatics at Denver Public Health – Director

Across the 1.9 million?

Howard Hays – Indian Health Services – Commissioned Officer

Across, yes, across our system, again, launched this summer, going into test in about two weeks, and using an open sourced solution for the NPI, using probabilistic matching for that, and then for those unresolved ones, there'll be some manual matching of people.

R. Scott Hawkins – Boston Health Care for the Homeless – CIO

...that's about how we do it. There's a master patient index in our health center controlled network. We have someone on our staff who spends a little bit of time every money trying to do some manual matches. Sometimes it's just a patient will let us know that they were at a different – and this would be a different provider. Our AD clinics all share one database. But that still doesn't make us immune from even last month we found a patient that uses a different name at three different clinics and it only accidentally came to light, and we have data analysts who, when we discovered that, merged them all together into one record, and put alias names together. I honestly don't know what happens to it when it gets to the master patient index at that point, but we clean up at least our own databases. Yes, that's sort of how it works.

Ian Erlich – Maniilaq Association – President & CEO

I think that that situation is not so much a problem as long as it's within the service area, like for instance Maniilaq Association. We have 12 villages that we serve, and our database serves everybody in that

whole 12 village area so that if you're in one village, and you go to the clinic, and then the next day you fly into Consuevee, and you're seeing at our facility, provided the data was already put into the system, it's going to pull up so that you see just what their visit was all about the day before. Within the service area, it's not too much of a problem, but it's when you get out of the service area where we have more difficulty. We used to have a multifacility integration system in Alaska where all the tribal sites would be able to exchange data, but that is no longer functioning. But as we move it to health information exchange, we should get that interoperability back.

Howard Hays – Indian Health Services – Commissioned Officer

We hosed that. Sorry.

R. Scott Hawkins – Boston Health Care for the Homeless – CIO

I mean, for us, we looked forward to portability of electronic health records. A lot of our patients are transitionally homeless. They're homeless now. They're homeless for maybe a month or two, and they're going to be housed again and on their way and probably never homeless again. And so our little piece of the record when we saw them for that one month is probably important to their overall care, and so how do we get it so that they can carry that on, how we can get to wherever they were before is a struggle. We struggle a lot, actually, with pediatrics and childhood vaccinations.

Boy, you know ... responsible for tracking childhood immunizations, but we're going to see that child once in that emergency shelter and never see them again. And we spend half of it trying to figure out where all their immunizations are, not trying to take care of the patient.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

All right, panel. Thank you so much for coming. It's an honor to kind of be here and have people travel from all over the country to tell us about their ... hard work, so it's really wonderful. Thanks a lot.

Howard Hays – Indian Health Services – Commissioned Officer

Thanks very much.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

So now we – you can have a seat, but please stay for the discussion, and now a discussion among the workgroup about themes and lessons from today. Would anyone particularly like to? I can begin if no one else would like to start, but—

Neil Calman - Institute for Family Health - President & Cofounder

I'll throw one out.

M

Yes, we all have lists.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

We'll merge them all at the end.

Neil Calman - Institute for Family Health - President & Cofounder

Should we do it by panel? I'm not competing with that.

W

No, I'm not either.

Christine Bechtel - National Partnership for Women & Families – VP

This is the part where Charlene.... I thought about, you know, was listening for two things: potential criteria and potential recommendations. I wish that I had thought of this for the patient family engagement hearing, but I'm wondering if we want to consider whether there are any actual recommendations that might come out of this hearing that would go to ONC that are not related to meaningful use criteria, but, for example, the ONC education campaign needing to leverage community organizations, you know, speak appropriate languages to engage consumers directly around IT. That was a theme that we heard, and that was an interesting recommendation.

Other recommendations, kinds of things, you know, research to understand the needs and characteristics of diverse populations, as they use health information and health information technology. I thought we heard a lot about expanding the scope of the RECs to do various things. One was work with consumers to become meaningful users of health IT. I think that's something we should talk about more. Expand their focus or, I think it's actually part of their focus, but recommend that RECs work with state Medicaid agencies to target those high volume, small practices for particular outreach and assistance to become meaningful users, making sure they're supporting patient engagement, and increasing cultural competency of physicians. I heard all of that around RECs, so I think that would be interesting to discuss at our next meeting.

Information exchange might need to include patient's primary language, so that pharmacists or other care team members who are accessing the exchange can be prepared to deliver services accordingly. And then the last thing that I heard from Ian, which I know nothing about, but I think is a completely appropriate role for the Office of the National Coordinator for Health IT, which is, is there a possibility to leverage the USAC money to purchase key IT hardware instead of just telephone technology. That was the sort of topical recommendation kind of things we might want.... Do you want my criteria list, or do you want to have a break? I'll give you my list.

Deven McGraw – Center for Democracy & Technology – Director

(Inaudible.)

Christine Bechtel - National Partnership for Women & Families – VP

Thank you, Deven. There were some really interesting, potential criteria to explore, so one was language appropriate health information and materials in an electronic format or online. One was the ability to export standardized data into a PHR, which I think is fabulous, personally. And the federal government itself is actually making some great progress. HHS or CMS and BA doing that out of their own data, which I guess is coming out in the fall.

Continue to do, of course, the data collection around race, ethnicity, and language, but adding some granularity to that, and I think that's something we've got to talk about because I heard some real challenges around local definitions and how do you aggregate that, and how do you use it for comparison? So actually beginning to report quality measures by those variables, and then, in future states, requiring the demonstration of culturally or linguistically appropriate intervention efforts to reduce disparities that show up in quality measure reports, which clearly would be like an attestation thing.

Mobile phones was a big thing. I think we've got to figure out that's a tough topic. I heard a lot on measures that I can assess out a little bit later, but one I think that was interesting was physical and behavioral health care coordination measures in particular. I heard kiosk in health facility for lots of different purposes: telehealth and recording patient preferences around preferred communication media, advanced directives, healthcare proxies, and treatment options. That's my summation.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Very good.

Christine Bechtel - National Partnership for Women & Families – VP

I've got it all in my chicken scratch, Josh. Don't panic.

Deven McGraw – Center for Democracy & Technology – Director

Actually, it was helpful, Christine. I think the one really strong theme that came out of this was the one size does not fit all concept and the notion of user centered design and the need to engage the communities, the more vulnerable communities that were the topic of the hearing today and the non-vulnerable communities. In other words, meet the patients where they are. Meet the providers where they are, which I think is a particular challenge for us because we have kind of a blunt lever for what we want to see in terms of what the systems ought to be able to do, and our best vehicle for doing that is the certification criteria.

But there was one suggestion that I heard about requiring, as part of meaningful use perhaps, and I think Christopher brought this up. An assessment that you have some sort of a requirement shaped in some way that I haven't fully assessed, thought through about requiring you to actually sit down and work with your populations about what it is that they need and in what format does it need to be delivered and incorporating that into whether it's EHR design or how you design your patient facing communications, however that might take place. But it came across, I think, pretty loud and clear in really all three panels that there is no one size fits all.

I think we would all agree with that, but then that raises the particular challenge of how do you create a set of meaningful use criteria and certification criteria that accommodate the fact that we cannot set the sort of one model that we think is going to work for everybody. And maybe it gets back to some of the discussion we had ... panel about what we're really seeking here is good outcomes. And if in fact the technology is designed in a way that supports that, and if our measures are going to start to evolve more towards outcomes, that may be the best way to get there. I don't know, but I think it's worth noting and thinking about some more.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Neil and then Charlene.

Neil Calman - Institute for Family Health - President & Cofounder

I don't have a comprehensive list, but there are a few things that sort of jump out at me. One is that we have to have a mechanism of monitoring whether we're increasing disparities through this rollout. I mean, every single written testimony and person who spoke started by saying if we don't get this right, we're going to do damage. And I think we've got to be able to monitor that part of it. You can't just start and say, well, let's just go at this. And so, if we get it wrong, we get it wrong.

I mean, it's not about just leaving people where they are. Things are going to get worse for people. Things are going to get worse because we're moving towards a more technologically driven solutions to problems, and as you do that, people will be less behind, and I think things will get worse. So we need to monitor that.

I think that to go to your list about the RECs, maybe that is a responsibility. Maybe that we need to monitor the ratio of providers who are serving vulnerable populations or safety net hospitals versus non-safety net hospitals in terms of stages of implementation. And we should be doing that, I think, at the

policy committee so that we can take that information and suggest policies in subsequent periods that tries to correct those problems if they occur.

What if we find out that the hospitals have chosen to, or that have been able to qualify that only 5% of the hospitals that are considered safety net hospitals have qualified when 25% of others have qualified. Are we just going to not do anything about that for the next year and just let it keep rolling out, and then the disparities keep widening? So I think we have to have a monitoring system in place, and we need to be able to look at what the definitions are of both the providers that we're going to monitor and others, so I would suggest that we start to think about things like what percentage of providers, of Medicaid providers by state are implementing compared with non-high volume Medicaid providers. Let the states, as part of their presentations to CMS, require that kind of reporting, both at the provider level, at the, you know, the physician level, and also at the hospital level.

And I think, on the outcome side, we really need to push for the stratified reporting of outcomes to know that we're not doing any damage. And I think we've got to start that in 2013, and we have to basically say, you know, because I'm hoping, though we don't know what's going to be called out yet, I'm hoping that in the 2011 criteria, we didn't lose the capture of race and ethnicity data upfront. But when the final stuff comes out, but if that's in there, then I think, by 2013, we need to start asking people to look at outcomes. And, to speak to Deven's piece, I think we should ask people, just like we do with quality improvement activities in our centers, we should ask people to report on things that are important in their population. I think we've got to get away from being so prescriptive.

Diabetes is not going to be the most important thing in every population, and I think we need to say what we need to know is if you're taking care of a population of people, what are the two or three most important clinical issues in the populations you're taking care of, and we'd like you to report on those by race and ethnicity and preferred language, and look at where there are disparities. And there will be disparities. This is not like look for disparities so we can slap you upside the head if you have. It's look for disparities because we know they exist, and we want you to put them clearly in focus in front of your eyes, so you can start to target interventions.

There are about six different ways that people used the term today "targeted interventions". I tried to capture a bunch of them because I want to copy them, but they're just, you know, the idea of finding the people most at need and targeting the work that we do, I think, is critical.

And I guess the last thing I'll say is I thought that there were at least three different people testified that we should use the IOM, that we should look at the IOM as the standard. For one, I don't think that we should be sitting around trying to develop some new standards. If a dozen people spent years challenging and looking at this and documenting 85 different ways that people do this and come up with a recommendation for a standard, hell, that's good enough for me, you know, and I think we should look at it. I'm not saying we should just adopt it willy-nilly, but we should look at it and see whether that's a very specific and concrete recommendation we could make to the standards committee to say this is the way we think race and ethnicity data should be captured, period.

Christine Bechtel - National Partnership for Women & Families – VP

It may actually be in the final because the proposed rule had the OMB defined standard, which was also in the IOM report for race and ethnicity. Language is really, I think, the key area where the trouble is, and so I know we've recommended in our comment letter that CMS draw from that report to do that because you have to define it in 2011 if you're collecting data on it. So I think it's an issue that has more....

Neil Calman - Institute for Family Health - President & Cofounder

Right, but is that granular ethnicity, or it's just the major OMB categories?

Christine Bechtel - National Partnership for Women & Families – VP

I think that is not granular ethnicity. It is the OMB categories, so you're....

Neil Calman - Institute for Family Health - President & Cofounder

We should look at that.

Christine Bechtel - National Partnership for Women & Families – VP

Yes, absolutely.

Neil Calman - Institute for Family Health - President & Cofounder

Yes, so we should look at that. There's probably more, but I'll let somebody else.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Charlene and then Paul.

Charlene Underwood - Siemens Medical - Director, Gov. & Industry Affairs

Yes. I'm going to add on. I think we heard a lot of themes from across all the panels around standardization, you know, so this was one in terms of, we don't need multiple different ways to report standards. If we're going to roll this out and ask providers to capture it, there's going to be a cost to capturing it, rolling it out and capturing it by providers, so there's a way that we can do it in a uniform way to get the value that we need, we really need to think through that.

One of the things that caught me on the exchange of information was, are we making sure that we capture, looking at data exchange end-to-end. So for instance, when we're talking about providing language appropriate patient information, it's not only capturing it as part of the "EHR", but when I communicate to SureScripts or the pharmacy system, I by the way tell them it's a Spanish speaking patient and we need to also be sensitive there. I'm not sure we do that today. We may capture that information, but some of this capability needs to be end-to-end to look at the standards. Again, I think we need to look at where this transcends a little bit.

I saw a lot of overlap with our patient engagement testimony, so I think we can build on that, you know, things like mobile and those types of things. And I think I sort of concur that as we're moving forward, the need for the flexibility, I think we heard that, the flexibility to meet the needs of the provider. And I think we heard the same thing in patient engagement. Each community will engage in a different way. So if there's a way to enable communities to engage there, all of their community and define programs around that that's going to enable them to get there, there may be – it may be where we can define standard to help them. I think that's a huge thing that we need to recommend. But, on the other hand, we also need to balance that with giving them the tools to do their job as best they can.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Sometimes my role is to distill and try to summarize, so I'll try to....

Deven McGraw – Center for Democracy & Technology – Director

Are you lumping?

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

I'm going to try to lump, yes.

Neil Calman - Institute for Family Health - President & Cofounder

Can we get a few more pieces out before you lump because otherwise they won't be included in your lumps?

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

I think, one, the common theme between what Deven said and what Charlene just said is the one size doesn't fit all. The other thing is the whole hammer thing. We only have the hammer, and it's not right for us to beat on everything.

The takeaway, I think, is that we have to, from a policy point of view, we want to provide the tools and enablers for people to get it as right as possible for their population. I think one of the things we did right was in stage one, have them capture the race, ethnicity, and language. We didn't quite specify the ethnicity, for example, and the IOM report actually came out after our final matrix. So what I did do was talk to the IOM, and they were going to prepare a letter to submit as part of the comment, so I believe that they, you know, CMS has their comment in terms of in response to the NPRM.

And I think the IOM recommendations were granular. Is that correct, Gina? Yes. Right, so I believe that CMS has at least the benefit of that submission. And the second point, I think, from an "outcomes" point of view, I think using that to create ... we said to stratify, even in our stage one, but maybe in our stage two and three, we can be a little bit more advanced in terms of what do you do with those stratified reports. Right now, we just said....

M

Do it internally.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Yes. Use stratified reports, but then that does become, I think, enablers. So combined with more standardized, granular ethnicity, and a requirement that systems be able to capture that, then I think using that will be a way of giving them the tools necessary because it'll go into the certification criteria to make changes that would produce better outcomes. So those, I think, were my takeaway messages from what is it that we can do in the meaningful use criteria, not overplaying the hammer, that would enable change in the organizations and the populations they serve?

Neil Calman - Institute for Family Health - President & Cofounder

Just to add something that might be able to be added our discussions about meaningful use, there are a lot of people who spoke about PHRs as a communication tool, and I think that that's really important because I think it's going to be a while before we can do this electronically, and that this stuff is going to capture. And I've always felt like the patient should be in the middle of the communication anyway, so this is really a way of making that real, so I would suggest that we really think about a requirement being the requirement to be able to upload in standard format into a PHR and that these un-tethered PRHs become a really, you know, become a major focus of what we look at in this next round.

I know that's consistent with what you're talking about, but it seems like a very important piece, given what everybody is saying, especially, you know, you are dealing with people who are very – a population of people who are very mobile, and we heard about prisons. We heard about people who are homeless. We heard about people are moving, migrants who are moving from place-to-place. I think that we need to think about all that. And if the PHR, if that's a way that we can capture information and have it be accessible to those populations, we should have that high up on our agenda as a requirement for 2013.

Art Davidson - Public Health Informatics at Denver Public Health – Director

I think everybody has provided a fair number of criteria and themes. I just wanted to emphasize one or maybe two that I thought were most important to me today, and it follows on what Neil just said about the PHRs. I think there's this piece about being able to upload to the PHR, but there was also the discussion about, you know, the multiple PHRs and then someone moving from one tethered PHR to a non-tethered environment, so we need to – I know this is not part of the HITECH scope, but we need to be able to say that the PHRs will also be able to efficiently communicate back using maybe even the CCD as the model for doing that. I feel like the PHR is in the middle and it's the closest thing that the patient is going to have, and we need to have a way for that to communicate to the next EHR that that patient may be encountering or getting care from.

The last thing, and again, this is not in our scope, but I think we heard today that in Indian country, as I think I heard it said, there's less Internet access than there is mobile technology. So I think that two years from now, mobile technology is going to probably be farther along in many ways than that Internet, and we have to make some progress around including the mobile technology as a way to communicate with and between patient and provider.

M

We might have to pick a specific thing like the alerts would be....

Art Davidson - Public Health Informatics at Denver Public Health – Director

Something that would help allow us to say we think this is important, and not to say that we're going to solve the whole problem, but just the beginnings.

M

Remind me, where did we end up, language and culturally appropriate health information materials? Patient educational materials were not patients in the NPRM.

M

We don't know what....

W

...they were....

M

Yes.

M

Yes.

M

Right, but we don't know....

M

So my point being that, to Paul's list, this would be another one that we could count in this direction, which is, they have to be language appropriate, because it wasn't. It's certainly one of the levers we've got to ask for it, even though it wasn't put in.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Okay. So thank you very much, everyone. Now we're going to move, Judy, back to you for the public comments.

Judy Sparrow – Office of the National Coordinator – Executive Director

Yes. Good meeting. Thank you. This is the public comment part of the meeting. Anybody in the audience here who wishes to make a comment, you can come up to one of the microphones. If you're on the phone, just press star, one, to speak. And if you're listening on the Web, please dial 1-877-705-2976 and remember to state your name, your organization, and you do have a three-minute time limit. Geniene?

Geniene Wilson – Institute for Family Health – Fellow

I'm Gina Wilson from the Institute for Family Health. I just wanted to mention one thing, which I didn't have time to discuss in my oral testimony. The IOM report also makes recommendations for language collection, which is slightly different than what we're getting now, so now we're asking for preferred language. The IOM report specifically recommends that we ask for spoken language preferred for healthcare. The reason that's so important is that someone may have one primary language that they speak at home, but they may prefer their healthcare information in a different language, so it's very important to ask that question specifically.

The second question is spoken language proficiency, spoken English proficiency, excuse me, and when I first saw that question, I thought, why would we need to ask that, but the more I think about it, and the more I've read about it, I think that's a very important question as well, so I just wanted to bring that up that those also include in the recommendations in the IOM report. Just, by the way, the spoken language preferred for healthcare question is how I'm training our front office staff to ask the question, and it's also how it is written on our registration form, but in our electronic health record, there's not enough room to write that out in the field, so I had to shorten it to language for health, which is the best I can do. But anyway, I just wanted to make sure you were aware. If you do think about adopting the IOM recommendations that those language questions are there also, and they're slightly different.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thank you. We don't have anybody on the telephone, so back to George.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

All right. Thank you.

Judy Sparrow – Office of the National Coordinator – Executive Director

Sorry. Go ahead.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Great. Thank you. Please.

Chantel Worzala – AMA – Senior Associate Director of Policy

Good afternoon. Chantel Worzala with the American Hospital Association. Thanks so much for a really great hearing on what is clearly a national priority of reducing and hopefully eliminating health disparities. I just want to echo what you heard from a number of folks that really the fundamental rule that we still haven't cracked of EHRs in supporting reductions in disparities is that standardized collection of data on race, ethnicity, and preferred language. Both to design interventions, but also to support policy and couldn't agree more on the need to agree for national standards on this.

What the IOM report put out were recommendations, but it will take some work to get from those recommendations to national agreement for what should be used throughout the federal government and in the field. But the hospital field has been working quite hard to improve this data collection and has

been through the Robert Wood Johnson Foundation funding, put out what is a toolkit for healthcare providers in standardizing data collection. This is a toolkit that has been endorsed by the National Quality Forum and really focuses on training those who will collect this data because it is something that you need to do with some sensitivity to make sure that you've answered questions about why the data are being collected and preserve that trust relationship.

I want to make sure that you understand it's not just we'll ask people to collect it – done. There's a whole process there of building educational materials and educating and training staff on sort of how to do it right. And we have a really good experience from the state of Massachusetts, which does require standardized data collection for race and ethnicity, and they did find, first of all, that it took some doing. It was good to do, and they were very appreciative of the data after the fact. But they also found that the electronic health records really did not, in many, many cases, support this standardized data collection, and there was a lot of very expensive and time consuming retrofitting of the EHR systems, so definitely things that moving toward agreement on the national standards and working with the EHR vendors to make sure that those technologies support this data collection and that we're helping providers do it in an effective way that allows people to self-identify their ethnicity and also preserves the trust relationship between providers.

I also wanted to just put forward an idea to move forward the national standards, which is that, I think, just today, ONC announced the first meeting of the enrollment workgroup, which will be making recommendations on standards to build into data systems that can cross social service programs and help with eligibility, verification, and enrollment into health insurance plans. Boy, wouldn't it be great if we had the same standards for collecting these kinds of data on that side, as we do in the electronic health records. So I'll leave you with that thought and let you know that we're more than happy to talk about these issues further and share the experience of Massachusetts and other places in trying to make this a reality. Thanks.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thanks, Chantel. We have one more commenter.

Todd Q. Adams – The Cave Institute

Thank you. My name is Todd Q. Adams with The Cave Institute. What I just wanted just to make a point that there's a lot of activity, synergistic activity going on in the broadband space, the healthcare space. As an example, the FCC released its national broadband plan, which where healthcare is one of the key verticals and, which is an area to address not only healthcare disparities, but also address the disparities in broadband adoption, not only in the communities of color, but also in rural communities also.

When you look at that as an example, there are areas where not only in that, but also in the U.S. Department of Commerce. In the Department of Broadband Technologies Opportunities Program, referred to as BTOP, one thing that's been indicated is outreach. Content that's linguistically appropriate, reaching out to specific communities, and that's exactly what those programs are doing in the areas of broadband adoption. But in order to have broadband adoption, you have to have applications and some services that are relevant to people, you know, PHRs, is what we're saying.

My point is that even within the different federal agencies, what I'm seeing is you see a set of recommendations, as an example, in the FCC national broadband plan. But there still seems to be a lot of work in terms of integration along, as it relates to stimulus funding and different departments, but there are things where there's not only an overlap in the demographics, the people being served, and some potential synergy amongst programs where you can accomplish not only addressing healthcare disparities, broadband adoption, and you can really gain some economies of scale by kind of looking at

where there's some commonality amongst the programs. I think that's something that's extremely important. One, the taxpayers would be happy to know, one, that there could be some economies of scale. Two, I think we would see some real traction as to addressing some of these issues. Three, they're just inextricably linked, so just thank you for your time.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thank you, Mr. Adams. Anyone else.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

All right. Very good. That closes this session. Thank you very much for coming.

Public Comment Received During the Meeting

1. IT developers need to consider making language material user friendly for staff - lovely to talk about providing it for patients - but those distributing material need to have a practical way of providing it to patients.
2. How do we see the Broadband.gov initiative affecting access?
3. Can we get contact information for the speakers? if possible all but very interested in the speaker from California.